
Martin Bodman / Moretonhampstead from Hingston Rocks

Devon Core 20 Plus 5 Community Connectors Programme (2022 – 2023)

Phase 1: People living with rural and coastal deprivation

North Dartmoor & Ilfracombe Evaluation Report

October 2023

CONTENTS

1. EXECUTIVE SUMMARY KEY LEARNINGS

Our Community Connector Teams captured and collated a data bank of 75 lived experience stories and testimonies during the project delivery period, providing a unique insight into people's experiences and views on a broad range of primary and secondary health and care services (see section 6).

We developed a steering group made up of the partners mentioned previously working alongside key individuals from the Health Inequality Programme Board and local Social Prescribers (both PCN and VCSE based).

The programme coordinators were also involved with the development of the evolving VCSE Assembly for Devon – a collective of VCSE organisations in the county that acts as a think tank for the sector and a communications route for other sectors to connect with.

We linked this vital work to the development of the ICS in Devon by ensuring that reports of progress are made to the relevant evolving ICS Local Care Partnerships to inform decision making and instigate change at a Place level.

We have a track record in Devon of providing peer support and shared learning with other systems and we ensured that the learning from the programme was included in the ICS wide People Led Change programme. We established a structure that creates a "pathway to power". Our findings have been shared with the Local Care Partnership to see whether a local place-based solution can be found where inequalities exist. If this is not possible, we have the opportunity to bring information to the Population Health Management Steering Group to ascertain whether a system wide approach/ change is needed.

During this phase, we recognised that people were looking at the wider issues of health inequalities in the context of things like the cost-of-living crisis, poverty etc. The Community Connectors, by establishing a trusted relationship by addressing immediate problems and challenges, were than able to engage people in dialogue about things that are traditionally health related.

The main issue that became a golden thread for both of our targeted geographical communities are barriers to accessing health services from a transport perspective (lack of public transport and having to pay upfront for long journeys to and from hospitals – especially radiotherapy and hospital discharge). Other key emergent themes were:

- Lack of access to free local antenatal and miscarriage support
- Positive experiences of NHS text messaging systems

- Staff shortages in hospitals
- Difficulties in accessing GP services/ getting appointments
- Need for more community based support services around the wider social determinants of health (eg lack of affordable rural housing is a health issue)
- Lack of GP referral routes for mental health therapy/ treatment
- Pharmacy staff shortages causing closures & delays
- Loss of local community hospital services
- Lack of local support for unpaid carers
- Lack of local residential care home capacity/ More local support required to enable older people to stay living independently at home
- No access to NHS dental treatment in rural & coastal communities for adults
- Appreciation of the value of local social prescribing/ community connector support services in rural & coastal communities
- Recognition of the value of local digital inclusion support services

Core 20 Plus 5 Rural Community Connector Volunteers were asked for their ideas of what could be done to improve how well their community supports health and wellbeing, and to suggest possible solutions:

- Need for Medical Centre to positively engage with stakeholders.
- Better transport links for people isolated by distance to access help. Not just for medical appointments but to allow access to employment, volunteering opportunities, social interactions etc
- More local 'joined up' thinking and planning and greater use of 'joint' monies
- Longer-term funding opportunities for proven beneficial services
- Encourage and enable people to question, rather than merely accept, advice and decisions made by medical professionals and/or automated systems.

Over the duration of the project, we have collected a whole host of case studies covering many issues often not relation to the 5 clinical areas of focus – e.g. dentistry has been a big issue in Ilfracombe. However, many of the issues people are telling us about are global infrastructure issues that are difficult to address on a local level. We have therefore decided to take our learning into Phase 2 of this programme by concentrating on issues that have regularly arisen in both Ilfracombe and North Dartmoor. In Ilfracombe, we will be concentrating on mental health particularly for young people living in deprivation and in North Dartmoor on COPD.

2. CONTEXT

2.1 National Context

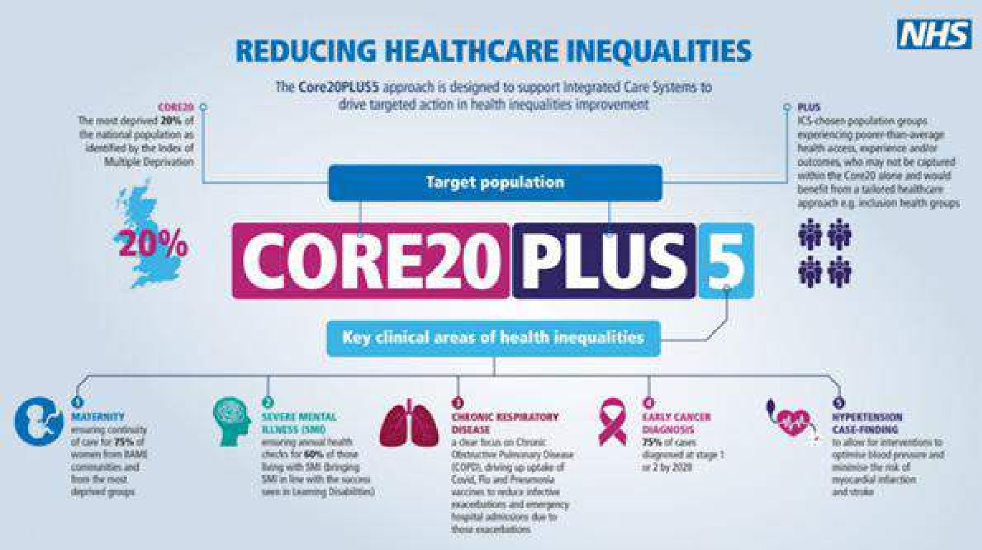
NHSE/I commissioned SCW to provide support and work jointly to design, mobilisation, and running the NHSE Health Inequalities Core20PLUS Community Connectors programme. The rationale of the programme is to develop and support community-based action on healthcare inequalities. The programme funds and supports a number of systems to develop and mobilise the model of Core20PLUS Connectors locally, through partnership with a VCSE organisation o to fund local co-ordination to build a network of local Core20PLUS Connectors, with learning and evaluation being built into the design.

Core 20 Plus 5 Community Connector Programme Objectives:

1. Community connectors are people who are part of those communities who are often not well supported by existing services, experience health inequalities, and who then help change these services to support their community better. This approach recognises that people and communities often know what they need and what would work, and that the NHS needs to hear from these communities
2. The Connectors programme will develop and support community-based roles to impact on the goals of Core20PLUS5 - acting as a voice to focus on barriers and enablers to reduce health inequalities and connect people with decision-makers.
3. This will include taking practical steps locally for health improvement in excluded communities experiencing healthcare inequalities, with focus on the five Core20Plus5 priority areas (continuity of maternity care, severe mental illness, severe respiratory disease, cancer, and cardio-vascular disease) and other locally identified priorities.

The Connectors programme is one of a number of funded initiatives that support focused action across ICSs to reduce healthcare inequalities across the five priority clinical themes and contribute to wider steps on health inequalities including upstream social determinants.

The Phase 1 delivery period was originally from June 2022 up to 31st March 2023, subsequently extended to September 2023. Core20PLUS Connectors will play a role that contributes to improvement trajectories at ICS / Place level across the five health and care priorities, and influence reduction in health inequalities across other locally identified priorities.   The approach defines a target population cohort – the 'Core20PLUS' – and identifies '5' focus clinical areas requiring accelerated improvement (see next page):



2.2 Local Context

Devon is not all what it appears to be. Economic activity remains higher than the England average, however the sectoral composition across Devon creates low and seasonal earnings of employment and a lack of social mobility. This impacts on a variety of wider determinant factors which influences health and wellbeing and exacerbates rural and coastal health inequalities.

Life expectancy has remained marginally similar over the last decade with people living their remaining 10 to 15 years of life in poorer health. This gap is starker across areas with higher deprivation as well as minority groups and different communities especially rural and coastal communities. Whilst improvements have been ascertained across some behaviour risk factors, more work is required to improve diet, physical activity, alcohol intake and smoking cessation. These are the leading behavioural risk factors which influence ill health and preventable mortality across Devon.

Premature preventable mortality has not changed significantly over the past 10 years. Poorer health can further manifest downstream. It can impact on the ability to work which leads to receipt of state benefits thus perpetuating income deprivation. It is an ever-decreasing circle resulting in stark health inequities between our haves and have nots.

Much of the work of Devon's Health Inequalities Programme Board has concentrated on major areas of concern e.g. a life expectancy difference of over 10 years between our most affluent communities and our most deprived or a 12% increase in hypertension depending on your income levels. However, we know there is much more we can do by listening to the experts on what it is like living with disparity i.e. people with lived experience in our communities.

We could have chosen a number of communities and populations to concentrate on, but we really want to explore health inequalities in both a coastal and rural setting. Therefore, we selected the following.

Ilfracombe - a coastal town in North Devon that has one of the highest rates of income deprivation in the UK and has huge disparities in health outcomes across mortality rates, early cancer diagnosis, smoking rates and levels of obesity.

North Dartmoor Primary Care Network Area – a geography that covers a number of rural towns and villages with an ageing population, high levels of mental health issues when compared to the rest of the county and a real challenge in terms of access to mainstream services.

The key element that links the two geographies together is that both have strong community networks and a vibrant Voluntary and Community Sector presence. It is also key that both areas have a strong culture of Social Prescription and community connection with statutory partners and VCSE organisations working closely together to deliver solutions designed by people themselves.

During the pandemic, both communities responded to the call for action by providing key support for their neighbours to ensure that no one was excluded. They did this with skill and expertise, and it is on these foundations that we believe we can build an even stronger network of community connectors to help address our biggest inequalities in the way communities want them to be addressed.

3. THEORY OF CHANGE METHODOLOGY

3.1 Delivery/ Co-Design Partnership

- Devon Communities Together (DCT) – The Rural Community Council for Devon, an independent asset-based community development charity and a member of the national network Action with Communities in Rural England (ACRE). DCT focusses on supporting rural communities to achieve positive outcomes and shape their own futures as thriving places for people to live and work.
- Encompass – A charity with a long-established footprint in Ilfracombe, specifically focused around people on low incomes and who are living in poverty and deprivation. They also offer a drop-in service in the heart of Ilfracombe which is accessible to both the community and wider stakeholders and a prime facility to support the work of the Core20plus connectors.
- North Devon Voluntary Services – A Council for Voluntary Service (CVS) that offers infrastructure support and volunteer coordination for VCSE partners in North Devon.
- One Ilfracombe – a broad partnership made up of statutory sector, private sector and VCSE sector partners that concentrate on the health and happiness of the 11,000 people that live in the town.
- Wellmoor CIC – A community-based health and wellbeing charity based in North East Dartmoor that promotes community led solutions.
- West Devon CVS – A CVS in West Devon that offers infrastructure support and volunteer coordination for VCSE partners in North Dartmoor.

3.2 Co-Design of a Theory of Change Framework

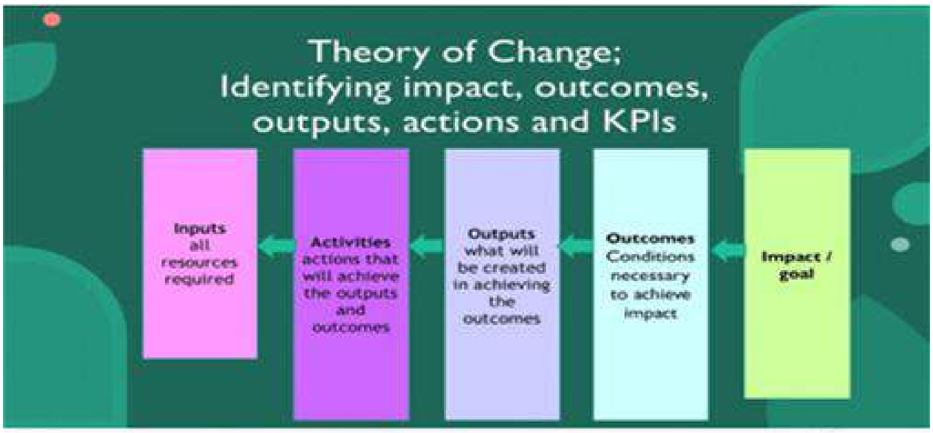
Devon Communities Together acted as critical support across both schemes and produced regular Theory of Change Impact evaluation reports and updates to enable us to learn and flex our approach as required. This impact evaluation report is based on the quarterly evidence reports, based on qualitative interviews and survey responses which have been collated using a Theory of Change Framework co-designed by local delivery partners in June and July 2022.

Devon Core20 + 5 Co-designed Theory of Change Objectives

Objective 1	Communities, partners, health and care providers, and decision makers have a better understanding of local needs relating to health inequalities through effective engagement, with more people having the opportunity to tell their story
Objective 2	People have a better understanding of support available, have improved confidence and motivation, and find it easier to access health and care
Objective 3	Volunteers and people with lived experiences are recognised as key contrubutors to the NHS Core 20 objectives

Our Theory of Change Framework included measurement of traditional outputs such as number of volunteers recruited, number of community events held, number of positive contacts made etc, but we focused on expanding our metric collection by involving people living in our communities of focus by creating a culture of lived experience story-telling and impact measurement.

Theory of change process:



This enabled us to create a patchwork of real-life stories telling us what did or didn't work, was their positive change (if there was any) sustainable, what was the knock on effect for friends and family and whether our project provided the catalyst for an improved outcome.

Both quantitative and qualitative data was collated by the local organisations and passed to Devon Communities Together to produce a complex community-based evaluation using Theory of Change methodology to develop an ethos of partnership and collaboration with people involved in the programme. The model for taking forward the Connectors programme is based firmly on community-driven / asset-based community development methodology.

Co-design your local connector programme

- Work with existing organisations with trust
- Learn from what already exists / assets (and invest in it)
- Speak to communities and ask them what will work.
- Define success in community terms not KPIs/targets

Recruit connectors

- Community Connectors must be local people (peer power)
- Have recent lived experience of inequality
- Have good current connections within their communities
- Engage people with the right attributes/traits
- Train and support them (prevent harm and progress)

Share power with communities

- Equal seats
- Long term relationship
- Accept responsibility
- Listen, get behind and fund what they think the solutions are
- Share anonymised data with them
- Work with them to address the issues – in partnership

3.3 Programme Delivery

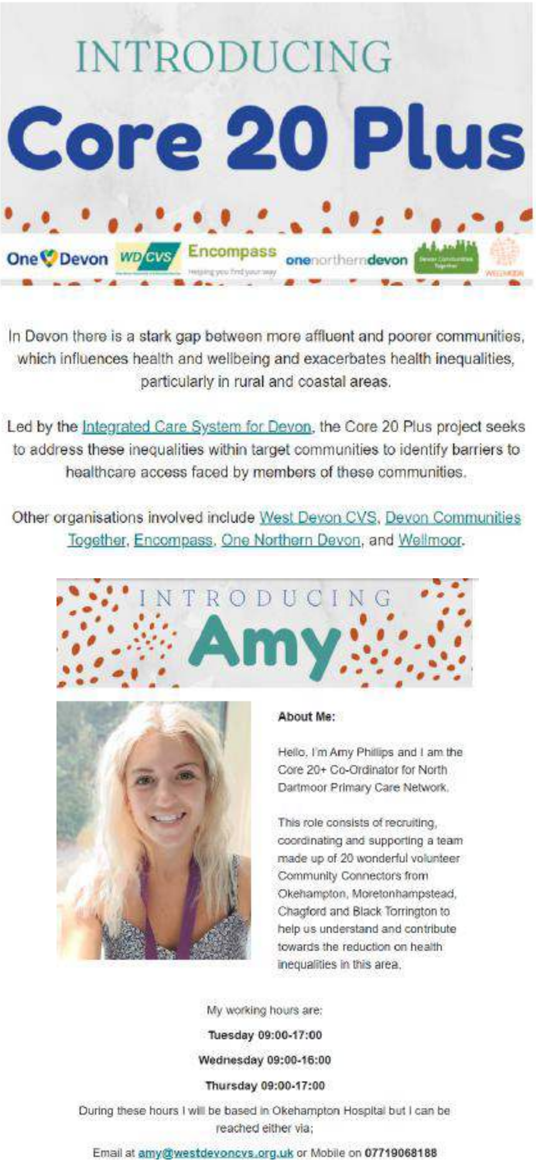
Our delivery model was based around two paid workers (Core20Plus Connectors) hosted by Encompass and West Devon CVS and working across each of the two geographies and in partnership with the other delivery partners. The paid workers recruited 11 Core20Plus volunteer ambassadors in each community with an emphasis on recruiting people with lived experience. Working with two distinct communities enabled us to employ a social research comparative method to see what works and what doesn't, getting under the skin of rural and coastal deprivation and the effect it has on health and happiness, as well as strengthening collaboration between the ICS and the VCSE sector. partnership with our colleagues in the voluntary and community sector.

To summarise, we will reach into the heart of our chosen communities working with people who are known and trusted. We will recruit volunteers based on lived experience and local knowledge to talk and engage with other people like them and we will learn from the journey taken by listening, talking and recording the real life impact that these conversations and interactions actually make – both those that have worked and those that haven't.

3.31 Delivery outputs reported in December 2022 Quarterly Report

- A project plan was co -created by the ICS and project delivery partners in June 2022. A Theory of Change evaluation framework was co-designed, supported by DCT who agreed with delivery partners the evidence to be collected to show the impact of the project. Workshops and meetings were held with all partners and with coordinators between June and September 2022.
- Training and resources session on citizen research methods was also provided for coordinators and volunteers between September and December 2022. As some volunteers were unsure how to kick off conversations about health, a document was compiled featuring advice from VCSE, ICS and Public Health partners, with the potential of offering face-to-face training on this topic for these volunteers.
- North Dartmoor: The Community Connector was recruited and began work in late August. Five community volunteers were recruited and trained, with induction and training completed virtually. Visits were made to a wellbeing café, a coffee hub and a community church to raise awareness of the project. Where people were willing to talk, they gave their stories anonymously and these were recorded for inclusion in this report. Online meetings were held with the PCN Advisory Group.

- Ilfracombe: The initial focus was on engaging with community groups across Ilfracombe, specifically One Ilfracombe who are well established in the area and have been able to connect us with both groups and individuals who are prepared to volunteer. These groups include, Pip and Jims drop in at the local church hall, The Candar Advice Centre, Salvation Army and Belle's place (a drop-in service for rough sleepers and those at risk of homelessness). Local delivery focused on targeting volunteer hospital drivers, of which there are currently 10 based in Ilfracombe as these are often the first people that many of our vulnerable community talk to and are well placed to collate qualitative evidence on the barriers they face in accessing health from a coastal community perspective.
- Posters and marketing materials were created and displayed in medical centres and key community areas, as well as via social media and local newsletters. Volunteers were given an online link to complete the initial questionnaire about how well they felt communities were supporting health and wellbeing were discussed with the coordinator. Community volunteers were asked at the beginning of their involvement how well they thought their community supported health and wellbeing. On a scale of 1-5, with 1 = not very well and 5 = well, three volunteers scored 3 and two scored 4.
- Wellmoor CIC created a communication strategy, designed flyers for use by coordinators and put together the first newsletter for the project.



INTRODUCING

Core 20 Plus

In Devon there is a stark gap between more affluent and poorer communities, which influences health and wellbeing and exacerbates health inequalities, particularly in rural and coastal areas.

Led by the Integrated Care System for Devon, the Core 20 Plus project seeks to address these inequalities within target communities to identify barriers to healthcare access faced by members of these communities.

Other organisations involved include West Devon CVS, Devon Communities Together, Encompass, One Northern Devon, and Wellmoor.

INTRODUCING

Amy

About Me:

Hello, I'm Amy Phillips and I am the Core 20+ Co-Ordinator for North Dartmoor Primary Care Network.

This role consists of recruiting, coordinating and supporting a team made up of 20 wonderful volunteer Community Connectors from Okehampton, Moretonhampstead, Chagford and Black Torrington to help us understand and contribute towards the reduction on health inequalities in this area.

My working hours are:

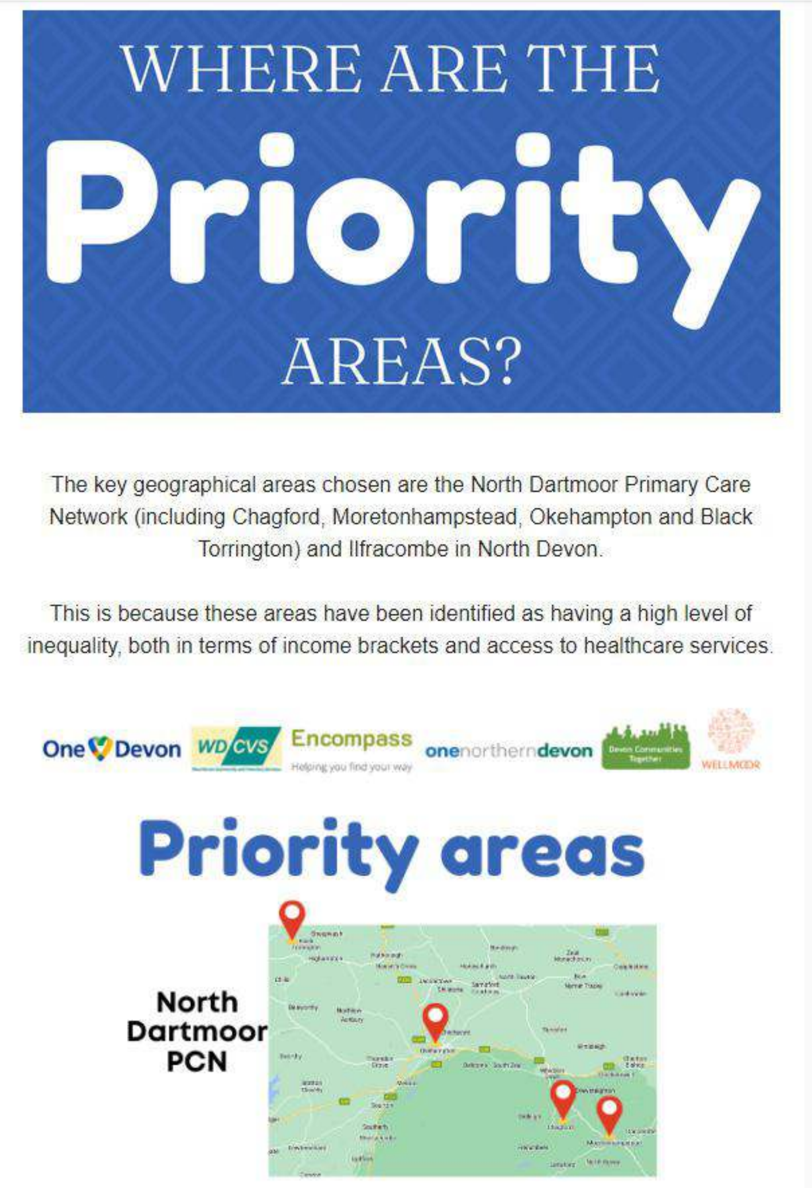
Tuesday 09:00-17:00

Wednesday 09:00-16:00

Thursday 09:00-17:00

During these hours I will be based in Okehampton Hospital but I can be reached either via;

Email at amy@westdevoncvs.org.uk or Mobile on **07719068188**



WHERE ARE THE Priority AREAS?

The key geographical areas chosen are the North Dartmoor Primary Care Network (including Chagford, Moretonhampstead, Okehampton and Black Torrington) and Ilfracombe in North Devon.

This is because these areas have been identified as having a high level of inequality, both in terms of income brackets and access to healthcare services.

One Devon WDCVS Encompass Helping you find your way onenortherndevon Devon Communities Together WELLMOOR

Priority areas

North Dartmoor PCN

Ilfracombe, North Devon

DO YOU THINK Healthcare SHOULD BE ACCESSIBLE TO ALL?

The aim of this project is to identify key barriers which lead to healthcare services being inaccessible to people in certain health outcomes, for example early cancer and high blood pressure diagnoses.

If you believe that everyone should have access to healthcare services, regardless of their location or income level, we would like to hear from you.

Volunteer

WITH US!

Do you want to help understand and contribute to the reduction of health inequalities?

We are looking for volunteers with local knowledge to talk and engage with other people like them and we will learn from the journey taken by listening, talking and recording the real-life impact of these conversations.

We need your help to ensure people who are living with poor health in your area receive the care they need to help them to live happier healthier and longer lives.

For more information about our volunteer roles, please contact Amy on 07719068188 or email amy@westdevoncvs.org.uk

3.32 Delivery outputs reported in March 2023 Quarterly Report

North Dartmoor:

A small team of 11 dedicated and committed volunteers, well integrated into local community and groups (5 from our larger town, 1 from our smallest village and 5 from our other remote villages that neighbour each other). We held an initial volunteer meet up event The Core 20 Connectors in Moretonhampstead met up with Amy from West Devon CVS in January to get started with conversations. Ideas were exchanged about potential barriers to accessing healthcare found in the rural communities in North East Dartmoor, such as lack of public transport and limited digital connectivity.

The Community Connector Team proactively engaged with:

- Okehampton Wellbeing and Walking groups;
- Okehampton Mental Health Group;
- Community Links Coffee Club in Okehampton;
- Older people in Moretonhampstead;
- North Dartmoor Hope Group for people with Chronic pain, Fibromyalgia, ME and Long Covid.

Moretonhampstead held a focus group in February 2022, to allow local people, including new volunteers, to discuss health concerns.

Ilfracombe:

Larger posters and flyers were created to distribute around Ilfracombe, with printers redoing the artwork and creating a professional flyer. The leaflets mention the coordinator's own experience of health inequalities and barriers, to help build relationships. As an incentive, each 'patient narrator' received a raffle ticket to be entered in a draw to win a hamper. The Connector Team proactively engaged with:

- The volunteering lead at the council
- The Community Transport Team;
- Local Residential Care Homes;
- Belle's Place Community Centre;
- The Public Health Outreach Team;
- The Salvation Army;
- Living Well Social Care Partnership
- Combe Coastal Medical Centre
- Together Drug and Alcohol Service
- Link Mental Health charity.

It soon became clear that the Community Connector role is about building people's trust in a short space of time. One barrier, post covid, was found to be that, when asked for narratives (or stories) about inequalities and barriers, there were people who were uncomfortable ***"Nothing bad said about the NHS"***.

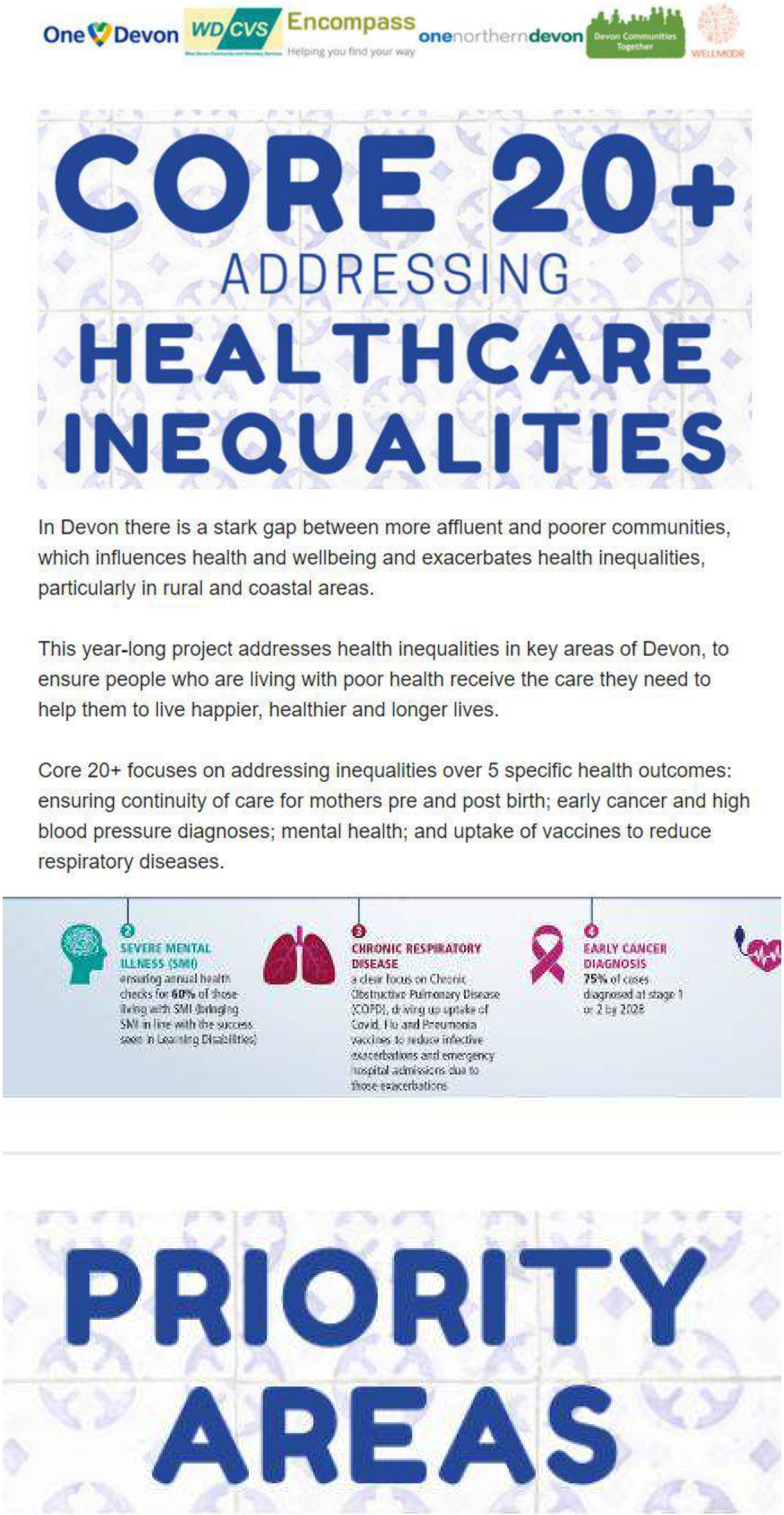
The Community Connector team was made up of 6 connectors, four were connected via the local transport coordinator, one was based at a local care facility and one was based at Belle's Place in Ilfracombe. Two of the volunteers have chronic respiratory disease; one has a severe mental illness; one has an early cancer diagnosis and one has hypertension. the significant demographic in Ilfracombe of an elderly, retired population who migrate from the inner cities. To many of them, the service they experience, is an improvement on their experience in the areas they have come from.

Intelligence from the health and community sectors was that health issues related to diet are a huge problem in Ilfracombe. A "wellness day" was held in March 2023, with the aim of starting to address one of the key underlying factors of ill-health in the area, poor diet. The Team involved a local chef and the theme of the day was eating for wellbeing, focussing on items that are commonly available in food banks, local produce and how to combine these ingredients to produce healthy meals.

After having conversations with people from the homeless community in Ilfracombe who frequent Belles Place (a café/support hub in the middle of the town), the Community Connector Team agreed with community podiatry services to deliver 4 half day drop-in sessions per year at the venue. This was regarded as a huge breakthrough and a direct result of talking and listening to people who seldom have the chance to tell us what matters to them.

The ICS secured funding for a pilot in Torbay to employ a Core20 Plus Connector Coordinator for the Core20 Plus CYP programme, employed by the Torbay Community Development Trust

The Theory of Change Evaluation Framework was updated regularly by DCT and Wellmoor CIC produced a second newsletter for the project.



CORE 20+
ADDRESSING
HEALTHCARE INEQUALITIES

In Devon there is a stark gap between more affluent and poorer communities, which influences health and wellbeing and exacerbates health inequalities, particularly in rural and coastal areas.

This year-long project addresses health inequalities in key areas of Devon, to ensure people who are living with poor health receive the care they need to help them to live happier, healthier and longer lives.

Core 20+ focuses on addressing inequalities over 5 specific health outcomes: ensuring continuity of care for mothers pre and post birth; early cancer and high blood pressure diagnoses; mental health; and uptake of vaccines to reduce respiratory diseases.

2 **SEVERE MENTAL ILLNESS (SMI)**
ensuring annual health checks for **60%** of those living with SMI (bringing SMI in line with the success seen in Learning Disabilities)

3 **CHRONIC RESPIRATORY DISEASE**
a clear focus on Chronic Obstructive Pulmonary Disease (COPD), driving up uptake of Covid, Flu and Pneumonia vaccines to reduce infective exacerbations and emergency hospital admissions due to those exacerbations

4 **EARLY CANCER DIAGNOSIS**
75% of cases diagnosed at stage 1 or 2 by 2028

PRIORITY AREAS

The areas identified as a priority for this project are the North Dartmoor PCN (Moretonhampstead, Chagford, Okehampton and Black Torrington) and Ilfracombe in North Devon. A Coordinator in each area is supporting the recruiting and training of volunteers with lived experience, local perspectives and insights to engage the local community.

WHERE ARE WE UP TO?

The Core 20 Connectors in Moretonhampstead met up with Amy from West Devon CVS to get started with conversations. Ideas were exchanged about potential barriers to accessing healthcare that would be found in the rural communities in North East Dartmoor, such as lack of public transport and limited digital connectivity.

EMERGING STORIES AND CASE STUDIES

NORTH DARTMOOR PCN
FOCUS: MATERNITY

In the North Dartmoor PCN area, a theme that seems to be emerging early on is based on the maternity services, or lack of. Case studies have been put together of women who experienced positive births and had no problems with delivery of service at the RD&E, but received limited prenatal care (i.e. antenatal classes, breast feeding sessions) and postnatal services.

One mother spoke of how she received no home visits and no mental health check ups. She recognised that she coped with the limited care on offer mainly due to the fact she was an experienced parent but if it had been her first baby it could have been very different.

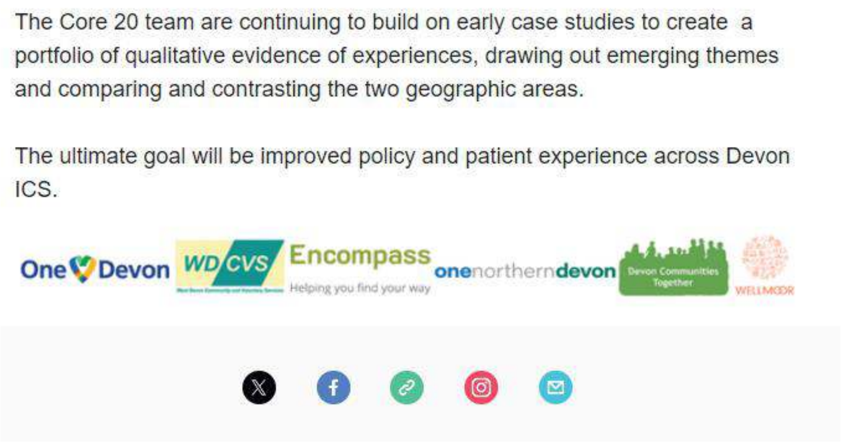
ILFRACOMBE AND DISTRICT
FOCUS: PROSTATE CANCER

In Ilfracombe there was a disparity between the counselling services offered to men and women for the effects of similar lifesaving treatment, with a case study reporting a lack of privacy and dignity in an exposed urgent situation.

In another case study an otherwise healthy and physically independent male patient attending an appointment to discuss a colonoscopy mentioned as an after thought that he had been having nightmares after witnessing a traumatic car accident.

Perhaps given the limited time or scarce psychological resources in North Devon, the doctor did not follow this up. PTSD is a major problem (related to addiction, the so-called "double trouble") which receives little or no teaching in medicine and nursing. Do health care professionals know how to recognise it?

WHERE NEXT?


The Core 20 team are continuing to build on early case studies to create a portfolio of qualitative evidence of experiences, drawing out emerging themes and comparing and contrasting the two geographic areas.

The ultimate goal will be improved policy and patient experience across Devon ICS.

3.33 Delivery outputs reported in June 2023 Quarterly Report

As the programme progressed, activity on the project was increasing and scaling up, due to new relationships being built and links being made in both localities. A Connector focus group was facilitated in April 2023, a co-designed half-day Learning & Support workshop was held to celebrate and reflect on the key milestones of the Community Connector programme. The recruitment of local volunteers slowed down during this period and the coordinators refocused on connecting people and gathering local stories. The Teams continued to connect within their local communities

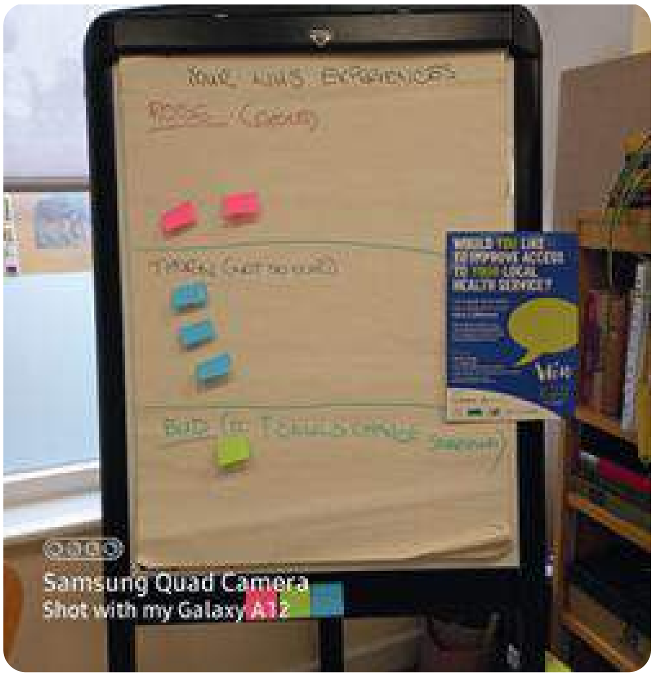
- Hosting a stand at One Ilfracombe Wellbeing Day in April 2023.
- Regular attendance at the One Ilfracombe Wellness group.
- The North Dartmoor Community Connector attended the North Dartmoor Mental Health Workshop Okehampton in May 2023

The work of the project was featured in the Okehampton Times and shared on their Facebook page, attracting a lot of comments. Please reproduce article from link.

Testimony from the North Dartmoor Community Connector Co-ordinator from this period:

> ***"Over the past few weeks, I feel like there has been a shift towards the project, people are getting excited about the stories we are bringing back to them and there seems to be potential for changes to take place off the back of what we've been told. I put together a questionnaire for the attendees of a local "Singing for Wellness" group that was aimed at those who were suffering with respiratory problems. The group was subsequently featured on BBC Spotlight where they discussed the positive impact the group has had on their condition and wellbeing.***
> https://www.bbc.co.uk/news/uk-england-devon-65309779
>
> ***"I found the most effective way of finding and hearing stories wasn't by inviting people to directly come and share with you but by making yourself a part of focus groups or gatherings that were already formed and then "gate crashing" towards the end. Indirect seemed to be much more effective. Possibly because relationships had already been formed, the space felt comfortable, and they felt they were in an environment that they could talk openly in. Group chats also then created a domino effect and once one person had started it wasn't long before the whole room was in discussion about their own personal experience of the healthcare services available. [cont.]***

> ***"Although the project is reaching its end now, I feel like in some ways this is just the beginning of the Core 20 project. People have shared their opinions and stories and experiences, and others have a genuine interest in seeing what can and should be done to improve them. We've lit the end of a very long, but exciting fuse! Let's hope great things come from the flame at the end".***



The Ilfracombe Team employeded the "Rose, Thorn and Bud" method of data retrieval in Ilfracombe which proved invaluable in capturing data and narratives. This strategy allows people to express their views quickly 'in passing'. Each person is asked if they can spare more time to expand on their experiences. This strategy was taken out into the streets during May 2023, to try and capture data which had previously been difficult to obtain.

3.34 Delivery outputs reported in September 2023 Quarterly Report

We continued our focus on "piggybacking" on local community services and events to collate lived experience stories from the two communities (see section 8).

Fuel Poverty Pilot - with winter pressures and the cost of living crisis coming very much to the forefront of conversations in both communities, we have decided to focus on 1 of the 5 issues Core 20 highlighted- COPD and respiratory diseases. We teamed up with the local energy providers for the North Devon PCN areas and through lists provided by the GP, we contacted individuals within the target cohorts to offer free energy efficiency home checks performed by their energy provider to create a healthier home environment, particularly with individuals with respiratory conditions.

We also continued to build key cross sectoral relationships between primary care and the VCSE sector in both sites. This has proved invaluable in that we are working with communities and bringing services to them in non traditional health settings (café's, community centres including vaccinations, blood pressure measurement, community podiatry and counselling services). We have also built strong relationships with Social Prescribers based in both PCN's and the VCSE.

4. KEY ACHIEVEMENTS

Activity and Outputs	Q3 2022/23	Q4 2022/23	Q1 2023/24	Q2 2023/24	Total 2022/23
No. of connectors recruited	5	6	0	0	**11**
No. of connectors trained	5	0	0	0	**5**
No. of connectors active	5	1	5	5	**16**

4.1 What worked well

North Dartmoor

- Local promotion, we reached out to areas via as many different avenues as possible- e.g. drop-in sessions in cafes; libraries; residential care homes; posters in all main medical centres; local magazine adverts in the Okelinks and Moorlinks newsletters and on the CVS Devon Connect online platform and social media via Facebook and Twitter.
- The community in the local areas that North Dartmoor covers already have a wide range of support groups etc that managed to engage with to hear the stories first hand, a lot of these groups are also linked to the Core 20 5 priority areas. By extending the target audience, we were able to obtain a diverse range of responses. Most people were happy to share stories once they fully understood the project and its purpose.
- We successfully prioritised engagement with community outreach groups/services set up by members of the community to fill in the gaps of services that are missing (e.g. local library running free baby weighing sessions and a well-being café set up in community as a safe space for people with mental health problems.
- We attended regular meetings with local PCN and the Health and Well-Being Alliance meetings and the Health Inequalities steering group to share learning and intelligence with system partners.

Ilfracombe:

- We worked hard to build a strong relationship across all connectors and groups and were able to tap into an already strongly connected community, to learn that residents didn't feel they had a vehicle to present peoples' stories to bring about system change. We were successful in presenting the core20Plus 5 model as being the vehicle they need to share the issues around inequality across Ilfracombe.
- We successfully recruited 6 community volunteers by extensive advertising and focussing

on building relationships with people, with a good success rate amongst local hospital drivers. Using raffle tickets for a hamper draw as an incentive was effective in enabling people to tell their stories anonymously.

- We have been particularly successful in collecting stories in group settings; unsurprisingly, people feel more confident than when they are approached individually. The relationships built by our connectors with their specific communities have been incredible. They have taken the time to get to know people and have integrated themselves into the key meetings and meeting places in their respective patches.

4.2 How we influenced barriers and enablers at service / system level

- We managed to get a GP service into a community setting for people who wouldn't consider walking into a surgery for a variety of societal reasons. This was comparatively easy to do once we had outlined the communities who were finding this procedural interaction difficult.
- The Co-ordinator attended the Northern Devon Equity Day to listen to Sir Michael Marmot talk about the factors which are impacting on people's health, specifically those people living in deprivation. The talk was both inspiring and concerning in equal measures and has provided a great backdrop to our work in Ilfracombe.
- We collaborated closely with the One Ilfracombe Community Development Team to identify and act upon common objectives.
- In May 2023, we shared learning and intelligence with the both the Population Health Management Steering Group and Delivery Group and in June 2023, we presented learning and intelligence to the One Devon NHS Integrated Care System Partnership Board (ICP).

4.3 How we influenced and impacted on Health Inequality priorities within communities?

- We set up a structure that creates a "pathway to power". Our programme findings on service issues, such as lack of/inconvenient transport links, difficulty making appointments and the admin associated with health and care were passed to the appropriate Local Care Partnership to see whether a local place-based solution could be found where inequalities exist. We were also offered the opportunity to bring information to the Health Inequality and Prevention Executive Steering Group and the RD&E hospital (Exeter) to ascertain whether a system wide approach is needed.
- The North Dartmoor Coordinator attended a mental health workshop run by Devon Mental Health Alliance to explore how communities can become a more "mental health friendly", as well as to recognise the achievements of local services and groups.
- Due to the fact that we chose at the beginning to concentrate on building relationships within deprived communities and not concentrate on specific health conditions, we have received intelligence and insight covering much more than the five health conditions covered by Core20. In hindsight, we possibly should have

narrowed our focus and indeed, we plan to do this moving forward. However, we have succeeded in sharing the priorities defined by communities with decision makers, particularly at a locality level and this will help to define and develop local services that people want where possible.

4.4 How we have influenced and impacted on the 5 core clinical focuses?

- We have largely taken the approach of encouraging people to talk about health-related issues in more a general manner, rather than targeting specific groups or asking people to talk about the 5 core issues. This has felt like a more natural way of encouraging people to open up and has allowed people to talk more easily about what is important to them. Through collecting a significant number of first person narratives, it became clear that many of the issues raised can have a direct impact on the care being received for the 5 core issues. This is what we are feeding back to local partnerships involved in decision-making for health and care in Devon.
- NHS Devon is currently undergoing an extensive restructure which will result in a new way of working. Key to this will be working more and more at a neighbourhood level through the 5 local care partnerships. The meetings attended above and those to be attended will be to assess the appetite for a scaling up of the Connector programme and to establish whether there is an available budget given the current challenges that NHS Devon faces.
- We have shared our learning with the wider system and decision makers in the ICS/ICP by having a regular slot at our Population Health Management Executive Steering Group, where we presented our findings on the 12th September 2023 to establish next steps with a possibility of preparing a budget line for 24/25 to scale up the community connector model (It is important to note that One Devon NHS is currently in SOF4 and therefore any funding requests will be heavily scrutinised).

5. OVERCOMING CHALLENGES

- The timescales needed to develop the relationships and trust that make a real difference with the people who don't want to engage or know how to are underestimated. The NHS must learn from VCSE partners that the key element on making this work is the relationship being the most important thing. It's not the topic you want to talk about. Volunteer recruitment, training, staffing etc all took much longer than originally anticipated, including three changes of Coordinator in Ilfracombe, due to unforeseeable circumstances. This led to a shift in focusing more on stories being heard than trying to boost volunteer numbers.
- It has proved to be a real challenge to extract the narratives from the people who wouldn't usually share. It's easy to hear the stories from those that shout the loudest but it's been tricky finding ways in and through to the people who go unnoticed and keep quiet.
- Local residents not feeling confident that their voices will be heard and that they can make a difference. Some local residents reported that everyone in the area already knows the health barriers they face (lack of transport/GP waiting times/local hospital closures) and so do the local NHS and they expressed frustration as to why something could not just be done to address these local barriers/ inequity of access. We also identified a significant element of scepticism from community members that "something like this has been done many years ago with no direct change or positive result". One big question raised was what can be done to address transport cost and access issues, when we are not funded to do so? For example, volunteers driving people to appointments are now old/poorly themselves and there are no new volunteers coming forwards. There is a growing feeling that a lot of the inequalities are down to inconsistencies in services in rural areas.
- Whilst the Community Connectors were provided with training on presenting stories in a variety of multi-media ways, the majority of people spoken to were unwilling to be filmed or recorded. With additional resources, the Connectors could have been upskilled in use of multi-media community engagement recording.

5.1 Areas of concern/issues raised by residents:

- In the comments on the Okehampton Times' Facebook page, in response to the article on the project, the majority were voicing their frustrations of the fact that more money had been "wasted on yet another report" when everyone knows what the issues are, mostly highlighting the closure of the local hospital; the pressure on the already busy medical centre; lack of reliable pharmacies and the rapid housing development in Okehampton and surrounding villages. This project has caused a lot of residents to feel angry at the idea that they are stating the obvious and repeating what has already been highlighted time and time again.
- In Ilfracombe, it was reported that prescriptions are sent electronically to the pharmacy but then regularly cannot be dispensed because there is no pharmacist. Patients are then told they can go to another pharmacy, which requires a new electronic prescription – but if the patient has no transport and a bus means taking children and/or other relatives this creates a significant barrier.

- A small number of patients reported being misdiagnosed by the GP in a 'telephone diagnosis' and several reported that their phone bill had increased because if they were transferred to the doctor to speak rather than have a call back then they paid for the call – also waiting time in a queue to get through it all meant a big phone charge – anything up to an hour and if they hung up they'd lose their place in the queue.

- A significant number of people were reluctant to share negative opinions or comments about the NHS because they know the state of it currently and the fact it is balancing on the edge. They are grateful for any bit of service they can receive because they understand that it is a thing to protect now, they aren't frustrated at the nurses, doctors, heath care workers on ground level, they're grateful for who they are and what they do- they are angry at the people higher up who pull the strings and make the decision based on generalised facts and figures and opinions rather than taking things into account at a local level. They are angry at the politics of it all.

- People are not generally interested in the 5 core clinical areas. They are interested in dentists (there are no NHS dentists in the Southwest, let alone North Devon, pharmacies (and lack of pharmacists at sudden notice) and radiology waiting times (5 weeks for an urgent result). Radiotherapy services centralised in Exeter, with multiple taxi costs reimbursable, but needing to be paid upfront by the patient. One cancer patient said "Forget trying to save your life if you don't have the taxi fare in the first place – anything from £80 - £150". A brand new radiotherapy department at NDDH cannot be used because it leaks radiation (allegedly – we have not been able to confirm this at the time of the report). One man in his 70s, previously active in local government and health boards told us "the NHS are only interested in things (illnesses) you can put numbers to – blood pressure and respiratory readings. No one seems to be interested in quality only quantity. The local mental health charity – The Link Centre – is in danger of closing. Once it does there is nowhere for people to go to get help."

- Our learning has been that we possibly spread our offer too thin (which proves it was accessible which is a positive) and we were not really prepared for the diversity and range of issues raised by people. We have had to be honest and say that the things we can influence and control, we will, but other issues are more challenging e.g. access to a NHS Dentist and barriers caused by inequalities in the broader social determinants of health (eg transport; housing; local economy etc).

- Having a blank page has meant at times that our community connectors have become a one person mini customer complaints service and this has been difficult for them because often it is something that is not in their control. Having more of a focused conversation point around specific health conditions will help this to be addressed in the next phase.

6. LIVED EXPERIENCE STORIES

Qualitative Data Anonymised Evidence Log

Primary & Secondary Care - Maternity Services

STORY 1: 30-Year-Old first time Mum, lives in Merton but is under the care of Black Torrington Doctors and Holsworthy Midwives. As this is her first baby, she has limited knowledge of what to expect surrounding the birth and before/after. She spoke to her Midwifery team about antenatal classes but due to funding and staffing issues they are unable offer them anymore in her area. Her only options were to find companies that offer the classes privately, but those courses would be more than £300, or travel to Exeter or further to attend the NHS led ones. Neither of them was a sensible option for her- she is currently off work with pregnancy related illness so financial things are already strained and developing and maintaining friendships with people in Exeter is unsustainable with a new-born, along with the weekly trips with over an hour-long journey to get there. She was left with no other options than to miss out on the classes and knowledge that is learnt through them, which has left a first time Mum in an even more overwhelmed and vulnerable state.

STORY 2: *"My husband and I experienced multiple miscarriages, (along with so many other women and families). I feel there was something lacking in the care and support we received whilst going through our losses, but also afterwards. Luckily, I now have a beautiful baby but after going through pregnancy after loss, I feel like there needs to be a change in the care given. That is why I'm proposing a new role within primary care that will provide a support service for those who are going through or have gone through miscarriage. I am putting together a proposal showing stats, proving the need for one, the training I will need to do the role, and how I plan to implement that role. I'm in talks with the Manager at Okehampton Medical Centre about the best process to do this and find funding etc, as well as putting out surveys on social media for people to fill in surrounding the subject."* Anonymous Female from Okehampton Area.

STORY 3: 'A' describes maternity care for her third child, born at RDE in March 2021. A lives in Doccombe, on Dartmoor and is in good health with a supportive family. There were scans at 12 and 20 weeks. She had induced delivery for all three births. The birth of her third child took 4.5 hours. A didn't see a doctor at any point during pregnancy, birth and aftercare.

What went well? Overall A was very happy with the maternity care and described the midwives as 'brilliant'. There was a real sense of NHS staff doing their very best in difficult circumstances. During pregnancy A had good regular contact with her local midwife at local GP surgery, which offers a good service and and timely appointments. The midwives in hospital were excellent. There were two midwives with her for the whole birth. They didn't have to leave for other births and there were no shift handovers. A was able to have her partner with her for the birth, which she felt was very important despite increased risk of COVID.

What could have been better? A would have liked her partner with her for scans. She feels this is very important even if this means an increase in COVID risk. At the time of the birth, RD&E was very full, and she had to wait 2 days for the induction to be carried out. Although A wasn't concerned about this. Although A was tested for COVID on her visits, her partner wasn't tested even though they were attending the birth. This wasn't explained and seemed an unnecessary risk. A was never sure who's care she was under, particularly in hospital and after the birth.

A believes her post-natal care was affected by COVID and was significantly less than she had with her first two babies. There were no home visits after the birth. She had only two follow-up appointments for which A had to travel to Ashburton and Newton Abbot to see the health visitor rather than her local GP. This wouldn't have been possible had A not had her own transport. Car journeys one-way for both were longer than the 20 mins max recommended for newborns. There were few follow-up phone calls, and no mental health checks for A. The baby was weighed at 8 weeks only. There were no mother and baby classes.

Overall there was noticeably less follow-up than with her first two babies. A noted this wasn't an issue for her and her baby as she is an experienced and confident new mum, but could have been significant for a mother or baby experiencing health issues. Mother and baby classes are very important to socialising for new mothers and their babies.

STORY 4: *"My daughter is 12 weeks old so I've recently used the maternity services available to me.*

Positives:

The text service to the health visitors is fantastic, I've used this a couple of times and have always found it super helpful.

When speaking to health visitors on the phone about my daughter having reflux, they were super attentive, helpful and didn't rush at all which is great as I usually find my GP rushes me due to lack of time.

My midwife throughout my pregnancy and when discharging me was amazing - I actually felt quite sad when she discharged me.

I had a fantastic experience when having my baby, the midwife and student midwife who helped deliver my daughter were both fantastic and made the experience amazing!

Negatives:

There are no free baby groups in this local area which means it's very difficult to meet other parents, share experiences and ask questions.

I was the only person to turn up to the antenatal class prior to me having my baby which was quite disheartening - I wish they postponed this until there was a busier class as I find it's good to hear what other parents ask.

I found the pre-baby antenatal class to be very much focussed on breast feeding and when asking about formula feeding the information was rushed - no one should ever put pressure on you breast feeding and shouldn't make you feel bad that you're considering not breast feeding. Expecting parents should be presented with ALL information and not be one sided!!

The postnatal group between 8-10 weeks I found to be useless - I didn't learn anything new and the lady who was running it I found to be extremely flaky and not super chatty it just seemed like a waste of an hour to be honest.

I've only seen a health visitor once when my daughter was 3 weeks old and haven't heard anything since; there is a major lack of support.

My 8-week check-up with the GP was fine however I felt that my worries and health concerns were dismissed. I lost my dad just 5 weeks after having my daughter and there was zero support from my GP regarding this so I've had to take it upon myself to get further help for my mental health

We were escorted out of the hospital by a nurse after being discharged from having my daughter - not sure why but this didn't sit right with me! We should have been able to walk out with OUR daughter on our own.

All in all, there is just a major lack of support prior to having your baby and post having your baby. When I speak to my sisters who had babies 10 years ago, they said that there were lots of free classes available and that there was a lot more support back then".

STORY 5: *"I had my baby last year in Exeter hospital. I was induced due to having low PAPP-A so was in hospital longer than I typically would have been otherwise. Unfortunately, my experience was not a positive one. I was ignored by midwives for pretty much my entire stay pre and post birth and made to feel belittled and inadequate which as a first-time mum, had quite a negative impact on my mental health. After being induced I was refused checks for almost 24 hours (despite my waters breaking and being in a lot of pain and discomfort). Each time I raised concerns/queries I was reminded that I was a first-time mum, and therefore didn't know anything. At one stage I requested additional pain relief, such as an epidural, as I was only given paracetamol, and was denied. I was finally examined when the midwives changed shifts the following morning and despite telling them I was feeling the urge to push (while still on a ward at this point) they still didn't believe me. However, when they did check, I was actually 9 centimetres and sent straight to a delivery suite from there. From there, the level of care I received improved, however, due to complications it ended in emergency forceps with a baby who was born back-to-back and with a cord which was too short. My husband asked in theatre how much longer I would have needed to be pushing and was told there was no way I would have naturally given birth. I asked to be discharged the following morning after a night of being ignored and receiving sub-standard care. My iron levels weren't checked until I was walking out of the ward where I was then told I was quite anaemic due to PPH during birth.*

While I am completely aware that my experience was solely caused by NHS services being underfunded and staffing levels being low, I cannot ignore that I received a poor service. If I was to have another baby, I would be opting for a homebirth as I feel that the 'risk' of not being in a hospital is actually as great as being in one. I hope that the research you are doing provides enough evidence to decision-makers that maternity services funding and staffing needs to be reviewed".

STORY 6: *"The weekly/bi weekly meetings with midwife were brief and non-personal, sometimes only 10 minutes to have basic checks on me, measure the bump and check baby heart rate. Issues for me started to occur when I had a different midwife do my weekly check-up (due to staff sickness). This midwife was concerned about my bump* *being 'big' compared to previous measurements, something my usual midwife was not concerned by. This led to being booked a growth scan and GD test, which I declined. This then led to a meeting with a consultant, who advised me to get a growth scan or I wouldn't be able to have the home birth I had planned. He told me the risks of having a 'big' baby, that my baby could DIE and wanted a hospital birth. This is with no evidence of a big baby, just a big bump. From this I requested no more bump measurements (fundal measurements??) from anyone and continued with my plan to birth at home. I was having a 'home birth against medical advice', therefore, midwives declined home visits prior to the birth. During labour, I had 3 separate shift changes of midwives over 2 days, all requested hospital transfers. I felt this was unnecessary so continued to labour at home, I was happy and felt safe at home. After many hours, I requested the midwives to leave the room as they were being extremely pushy, wanting to break my waters, asking lots of questions, checking heart rate, not listening to me and generally being very rude to my partner. Midwives even told my mum that my uterus would explode... Thankfully my mum works in birth and knew that was not possible. They sent two ambulances to my house, which sat outside of hours (huge waste of resources). Baby was born super healthy, 8lb so not particularly 'big'. The midwives then checked me and the baby and sat in a separate room to write up notes for 3 hours!*

I had 1 home visit 3 days after birth, very brief check of baby. I was requested to go into hospital to have baby weighted at 5 days old as they couldn't do a home visit, I declined. So had to go to Totnes instead, again very short visit with midwife. Never saw or heard from them again.

I had 1 meeting with health visitor at 6 weeks to do hearing test. I was never contacted again by health visitor or medical professional. Luckily, I didn't need anything from them but felt very strange after weekly meeting from 20 weeks of pregnancy. This experience definitely made me not want to use the NHS maternity services if I choose to have another child".

STORY 7: Core 20 +5 Focus Group Moretonhampstead Community Hall. 24-02-23.

C2: Describes birthing experiences (2x children). First birth she was imagining/preparing for was a hypnotherapy birth. A fairly recent arrival to the locale, she didn't know how to connect with other mums-to-be. Was in the birthing pool when her waters broke and the mood changed in the hypnobirthing room as the baby was breach. The midwife had missed this crucial diagnosis. C was taken to Torbay hospital and managed to give birth with no pain relief. Thankful to be in the hands of an 'amazing' doctor who reassured her by explaining recent peer-reviewed research that breach births were possible if the mums were allowed to follow their instincts. C appreciated being spoken to like an intelligent human being. She expected to have a caesarean but was able to deliver her daughter vaginally and felt very empowered and 'superhuman' as a result. The doctor had made a dangerous situation a positive experience.

Second birth was also positive. Aftercare also was good, e.g she was freaking out about daughter soon after birth and received immediate, reassuring support from Doctor at Moreton Health Centre.

Her sons' weight dropped and 'the Red Book' tells you to go to a weighing place in Teignmouth, although there are scales at the Moreton Health Centre.

She comments on the importance of having GPs that know you, one of the plus points of rural healthcare, as opposed to having multiple surgery GPs and no single relationship.

Primary Care / GP Services

STORY 8: *"This immediately brings to mind a current and contentious issue for patients using the Hatherleigh Medical Centre. As you probably know, this practice is owned and managed by Ruby Country Medical Group in Holsworthy. Patients cannot ring Hatherleigh direct, they have to ring Holsworthy; getting through to Holsworthy often takes an age; sometimes all callers get is a recorded message asking them to try later; when they do get through they can speak only to a receptionist, many of whom are neither knowledgeable or helpful! There is one lady in Hatherleigh who has been agitating about this for some time - a lot of discussion on the Nextdoor Hatherleigh website, emails and letters to Ruby Country - without any meaningful response."*

STORY 9: Mr & Mrs P (Ilfracombe) wanted help with completing a health assessment form. Mr P can write and read only a little. Mrs P has learning difficulties and is dependent on Mr P. Mr P is a self-confessed alcoholic who drinks alcohol sometimes. I asked him if he had gone to rehab for drug and alcohol, and he said no, it was too expensive and he couldn't leave his wife. I also asked if he could attend 12 Step meetings (AA), and he had not heard of those. He had not heard of a local drug and alcohol service either.

The health assessment form concerned getting Mr and Mrs P into more appropriate accommodation. They had been evicted from their previous accommodation because they were 'messy' residents. I am not entirely sure who gave Mr P the health assessment form to complete, but not being able to read and write is a barrier to services that require many forms that people are required to complete. And I wondered why someone had not checked that he could not read and write. The main problem seems to be that when Mr. and Mrs. P. were evicted from their previous accommodation, which was on level ground, they were then rehoused in a caravan trailer/holiday park on a hill. Mrs. P. has severe asthma and breathing difficulties. Even crossing the walkway from the library to the Candar Centre (about 10 m on a slight incline), I witnessed Mrs P standing and bending over a small wall to catch her breath. Mrs. P's asthma is maintained and controlled by two inhalers.

Mrs. P. has also been diagnosed with an overactive bladder, which has many causes, but could be related to a right CVA with weakness on the left side 7 years ago. No other causes have been explored or investigated. She has not been referred to an incontinence nurse specialist. This is an issue, because Mr. P is currently disposing of her used incontinence pads in general waste. Any material containing bodily fluids must be disposed of as clinical waste in yellow clinical waste bags. I have advised Mr. P to go to his GP to find out where he can get a supply of these. This is an infection control issue. Mr. P has to wash several changes in bed linen per day. He also has to wash the seat and chair covers. He has to pay for the laundrette on the campsite, and it is expensive. Mr P receives a carer's allowance.

STORY 10: Mrs G came to the Candar Centre asking for help with some forms to complete. She has various forms and doesn't know which to prioritise, because they come from different organisations/departments, but are about the same thing (electricity). I don't think this was a specific issue with the NHS, but her comment was (after saying she would not hear anything bad about the NHS, a common theme), "The NHS has too many managers and not enough people doing the real work. No one seems to know what each other is doing". I gave my contact details to her as a friend of her's has had some difficulties with the NHS.

STORY 11: A young woman from Petrockstowe told of how she struggles due to no public transport in and out of her village and her not being able to drive. She recently spoke to her GP about her concerns surrounding possibly having Autism. The GP she was didn't know how to make a referral to the appropriate team so advised her to rebook with another GP; she did so and when she arrived at the appointment she had been booked with that same GP so she left without even attending the appointment. The third attempt at an appointment was finally with a different GP and someone who was able to make the referral. She then received a letter stating that she is on the list for an Autism assessment but the wait time is currently 4 years. She has had no further advice or help on the condition or situation she has found herself in.

STORY 12: A man finds that the E-Consult the GP surgeries have been using since covid is not as straightforward as they lead you to believe. He has been unable to use them to book appointments or speak to a GP and has as a result enrolled on a computed course to try and help. He said that when you're feeling ill or in need of a doctor the last thing you need is the added stress of trying to fight with technology. He misses being able to speak to a friendly receptionist who was always more than accommodating with booking appointments and queries.

STORY 13: *"It is the worst medical practice I've come across in 50 plus years. I've been a patient for one and a half years, required no visits to the surgery as nothing wrong. When my back went, they didn't respond for four days leaving me in agony. Then they wanted me to drive (impossible with that condition) to pick up a prescription. My partner could pick one up from a chemist in Okehampton but they can't do that as they don't do electronic prescriptions unlike every other practice around here. In the interim I've seen (at my own cost) a private physio, osteo and chiropractor."*

STORY 14: Chagford Memory and Community Café 12th May 2023

Person D is an elderly lady who had a good experience with a lump removal. When she felt a lump in her breast, she went to visit the GP and it was dealt with extremely quickly. Her treatment at the hospital was excellent.

STORY 15: Chagford Memory and Community Café 12th May 2023

Person J said access to the GPs in Chagford is very good. They can generally see you at short notice, and if they can't see you, they will phone you.

His wife has a number of problems including AF, COPD and peripheral neuropathy. When he spoke to his GP on the phone, they asked him some questions and then asked him to bring her in. The GP then referred them directly to hospital after testing her oxygen levels and finding they were very low. He felt that it was dealt with extremely quickly and well. Unfortunately, while she was in hospital, she contracted covid. And was put in isolation for three weeks.

During that time, she did not receive any visits from the physio or OT. The first visit from an OT was on her last day when they picked her up. He said, *"they expected her to be able to walk out of hospital after being bed bound for weeks."*

STORY 16: Chagford Memory and Community Café 24th February 2023

A volunteer driver for the District Community Transport Group* in Okehampton was more than happy to share a story that he had heard whilst on a journey with a user once after hearing about the Core 20 project.

*a community led service (Registered Charity: 1024617), supported by Devon County Council and West Devon Borough Council, committed to providing access to transport for the local community - especially for people who find it physically difficult to use conventional public transport, the elderly and those who are rurally isolated. All drivers are doing so in a voluntary role.

"This immediately brings to mind a current and contentious issue for patients using the Hatherleigh Medical Centre. As you probably know, this practice is owned and managed by Ruby Country Medical Group in Holsworthy. Patients cannot ring Hatherleigh direct; they have to ring Holsworthy; getting through to Holsworthy often takes an age; sometimes all callers get is a recorded message asking them to try later; when they do get through, they can speak only to a receptionist, many of whom are neither knowledgeable or helpful! There is one lady in Hatherleigh who has been agitating about this for some time - a lot of discussion on the Nextdoor Hatherleigh website, emails and letters to Ruby Country - without any meaningful response.

That is all by way of saying that I know there are issues about which individuals feel frustrated and powerless. Having those issues brought to official attention through an accredited channel like West Devon CVS can only be a step in the right direction."

STORY 17: Core 20 +5 Focus Group Moretonhampstead Community Hall 24th February 2023

There was a discussion about wet rooms in the health centre for seniors to use with or without assistance. A £5.00 'bathing service' once existed in Chagford (Cranleigh Gardens). A change of health authority led to its closure, and again there is some dismay about the disappearances of peripheral community health services like these.

STORY 18: Core 20 +5 Focus Group Moretonhampstead Community Hall 24th February 2023

M: Grandson has eczema condition and it was a battle with GP's in Chagford to obtain a dermatology referral to Exeter RD&E. As a trained healthcare visitor, mum knew to contact RD&E and get advice on what to say to GP's. A referral was then eventually given.

The system can be impermeable and opaque, difficult to navigate, and GPs don't always believe their patients, or make referral decisions according to budgets and resources available, rather than actual healthcare needs, or are too rigid regarding NICE guidelines. But when appointments and referrals are successfully made the healthcare experience is generally good.

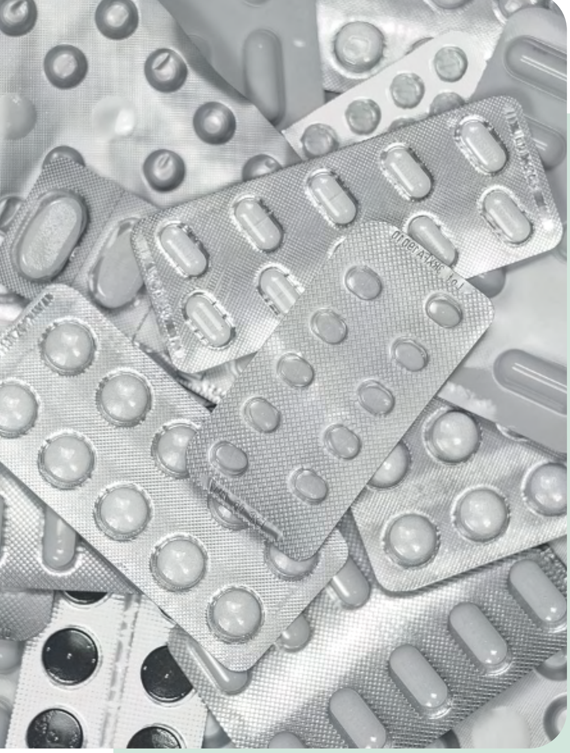
Primary Care - Mental Health Services

STORY 20: Participant (North Dartmoor) has a son, early 20`s, who is totally shy and anti - social, suffering from Asperger’s syndrome and with a complex over his excessive height. Having recently moved to the area both feel lonely and isolated. Whilst willing to talk about the condition the mother cannot seem to elicit help or a referral from her GP. Status: stalemate!

STORY 21: One young man talked about the lack of mental health services in the area. He had had no active support for over 1 year despite suffering with mental health problems for most of his life. He was on a waiting list for a CBT course but was unable to get on due to staffing numbers so he was discharged after waiting for 18 months. He was left no alternative options or suggestions. His GP is of the opinion that he is attending support groups set up by a volunteer charity and that is sufficient help and no more is needed. He commented that his GP is always happy to just prescribe more pills rather than get to the root cause of the problem; he doesn’t want to be dependent on medication for the rest of his life. When he was living in Manchester he was able to access the higher level of help he needed but when asked why it couldn’t be offered here he was told it was due to “*no resources*”.

STORY 22: Ms A acts as an informal helper for Mr E (Ilfracombe). She revealed she is now ready to tackle the abuse she received in her childhood (some 50 years ago). She has waited 10 months for an assessment and then there is a 2 year waiting list for therapy.

STORY 23: Mr W brought in a letter from “Wellness Health Assessment”. I met Mr W at a Trauma, Mental Health and Addiction Conference I attended and participated in (24th May 2023). He has a history of childhood sexual abuse, depression and suicide ideation. I have an anonymous copy of this letter (with his consent). There is a lengthy assessment where it is clear he, and he feels, needs professional therapeutic intervention but he has been directed to online resources which he feels is unacceptable because a computer with a WIFI is required which means a visit to the library or the Candar Centre, knowledge and skill in IT and the motivation to access these resources which is not possible when experiencing depression.



Primary Care - Pharmacy Services

STORY 24: Superdrug Ilfracombe (Pharmacy section) – closed all day 15th February 2023 (unable to get a pharmacist).“Absolute shame on Lloyds, your lovely professional staff are constantly getting abused from customers experiencing long queues because of the lack of staff in the Ilfracombe branch”.

“Nearest pharmacy is in the next town, a 22-minute car-ride away. However, the electronic prescription would have already been sent to one of these two Ilfracombe town centre shops, so it is sitting there on the computer waiting to be dispensed; pointless going anywhere else. What happens with recovering Substance Use Disorder (SUD) patients who are on a daily prescription and pick-up of substitute medication (methadone, buprenorphine etc.)”.

STORY 25: One North Dartmoor resident ended up in hospital twice after the chemist was unable to give her the prescribed insulin prescription over 2 weeks after it was ordered and sent to them. They had no explanation as to why she was unable to collect it and even the GP queried it, to no avail.

STORY 26: A North Dartmoor resident tried for over 3 weeks to collect her prescribed inhalers but was unable to due to sudden and unexpected shop closures apparently down to staffing issues. Even when ringing to sort an alternative she was unable to reach anyone.

STORY 27: One North Dartmoor man shared an experience on behalf of an elderly friend of his. He told me that despite paying for delivery of her prescription she had been forced to wait 2 weeks for it to arrive, no explanation or apology provided. She tried ringing numerous times to query and chase it but no answer.

Primary Care - Community Nursing Service

STORY 28: A gentleman had an operation leaving him with a 4cm deep/4.5cm long wound that needed dressing daily whilst at home. He had no issues getting it dressed Monday-Friday but all medical assistance became obsolete on the weekends. He lived alone but was expected to travel to a hospital further afield and over 30minutes drive away despite the fact he was unable to sit down for long periods due to the wound location. He even tried self-referring to the Community Nurses in the hope they may be able to help in the interim but his referral was rejected without reasoning.

Primary Care - Community Hospital Service

STORY 29: A man new to the area unknowingly went to the local community hospital looking for A&E as his wife had cut her finger whilst gardening. Whilst they were there ringing bells trying to provoke a response, they were joined by a pair of frantic parents with a baby who had fallen and was in and out of consciousness. They had rung 999 but there were no ambulances available to help or even see them. There was no answer at the hospital as it is no longer a working hospital and doesn't operate on the weekends. They had nowhere locally to go to find help. A friend of the gentleman's was a surgeon and advised them all to go to A&E over 34 miles away (a really long journey to make with an unwell baby) which turned into a 3.5hour wait. Luckily both the man's wife and the baby were ok but he made the comment that *"surely with all the new houses being built there should be provisions in place for at least a minor injuries unit that operates for longer than the weekday times at present"*.

STORY 30 A man reported that having been a carer for elderly relatives in the local town he came to dread the weekends/holidays when no practical medical help was available locally. He now travels a nearly 100-mile round trip to another hospital's A and E because of better resources and bearable waiting times. He believes the community hospital needs to be opened again to help unblock beds in the larger hospitals and free up ambulances.

STORY 31: I recently met with a lady who is heavily involved in the petitions to get Okehampton Community Hospital open again. She was able to give me some examples of how people had faced health inequalities because of it being closed.

Primary Care - Covid Services

STORY 32: *"In September 2021 I moved from Hackney, London back to NE Dartmoor, where I grew up, to be nearer to my aging parents in Manaton and to do a health science degree in Plymouth in a bid to switch career from arts to health.*

It was a real struggle to find affordable accommodation in NE Dartmoor- during August and September of 2021 there were on average 8 advertised long-term lets on the whole of Dartmoor. Most accommodation was available only as temporary holiday lets, Airbnb etc.

I resorted to staying with a friend of a friend who had plenty of space in her large country home near to Moretonhampstead for a small sum, on the understanding that it was time-limited, but it felt a bit like an imposition. After 3 weeks of staying there, in mid-October I got ill and realised it might be Covid.

I cycled to Moretonhampstead to get a rapid testing kit from the chemist. Not knowing where to safely test I went to the car park to administer the test and sure enough it was positive. I called my hostess and she asked me not to come back into the house because her daughters were visiting. As I was not a 'tenant' but a guest I had no rights. At this point I started to panic as I realised I had nowhere to go that was safe for me or for other people. The advice was (and still is) to stay at

home if you have the coronavirus. But what if you don't have a home? I called the NHS covid Test and Trace for advice and support and got neither. I spoke to a young woman who seemed completely out of her depth, clueless and unknowledgeable. I remember thinking, wow, 37 billion spent on badly trained telephone operatives. Not good.

I knew that Hackney council were running 'covid hotels' in the borough for people with the virus who couldn't stay at home. Were Teignbridge council doing the same? Still sitting outside in the car park feeling very ill and breathless I called Teignbridge but couldn't get through to anyone. Even if they were providing accommodation (which they weren't) there was no way I could take public transport to any of the towns or cities. I called a self-contained holiday cottage service near Moretonhampstead but they said they couldn't help. Eventually I had no option but to stay at my vulnerable, elderly parents' house in Manaton in their spare room, running the risk of infecting them and making them seriously sick. It was a very scary time and I had to cycle myself from Moretonhampstead to Manaton in a very ill state and was collapsed for 7 days. I do feel that it has impacted my health in the longer term - I used to be much fitter before that episode.

The key general message here is that the lack of affordable housing in rural areas IS a public health issue. There is a lot of empty accommodation in rural areas that are kept as passive income, denying the basic right to long term housing in the area. But specifically, during the pandemic there should have been provision in every rural area to accommodate infected people without housing. It is not within the NHS remit to provide housing, but it is in the councils' remit, and those with second homes and holiday lets should be taxed appropriately."

STORY 33: Chagford Memory and Community Café 12th May 2023

Person F had been frustrated trying to book a covid booster for herself and a friend. On the first instance of calling, she was informed that they were only able to make bookings within the next week. When she was not able to make any of the available options, they asked her to call back closer to the time. When she called back in after a few days she was on the phone for 20 minutes before being cut off. On the third time of calling, they told her that the only available appointment was on the same day. On each occasion she was asked to give her all of her own details and the details of her friend before they were able to tell her which appointments were available.

She said *"this was difficult for me and I'm fairly competent. I don't know what it would be like, for somebody who was less able. I'm almost on the verge of not bothering. It was much better before when they were able to do the boosters in Chagford. Or I'd prefer to just be given an appointment on a certain day, like it was when we last had to go to Okehampton."*

STORY 34: Chagford Memory and Community Café 12th May 2023

Person G has a chronic kidney disorder that was diagnosed when she was in her 80s. She had suffered for some time from high blood pressure which had become increasingly bad after her husband had died. She was given pills for the high blood pressure, and the dosage was gradually increased until she reached the strongest dosage that was available.

The GP sent her to hospital for tests in which they diagnosed the issue with her kidneys. She is now taking pills generally prescribed to diabetic people. It has helped her blood pressure, but it gives her very bad constipation and soreness.

Her mobility is not good and she does not drive and neither does her son who has mental health problems. When she had to attend an appointment for a covid vaccination she was not sure she was going to be able to make it. She heard that somebody else from the community was going and managed to organise a lift that way.

Primary Care - Carer Support

STORY 35: I recently had a highly emotive phone conversation with a lady who is an unpaid carer for her husband who has Primary Progressive MS. She has been caring for him since 2009 and has been doing what she calls "heavy care" since 2013. This is when he became wheelchair dependant. Ideally this conversation would have taken place face to face and been recorded but the nature of her role now means that was unfortunately not an option and telephone was the only practical way of communication.

Extracts of our conversation are as follows.

"My husband was finally given an MS diagnosis in 2009, following a 4 year wait and battle. He has been wheelchair dependent since 2 013. Unfortunately, the diagnosis he has been given is Primary Progressive MS- not the bog-standard Relaxing Remitting MS. All the research, drug therapies, help and advice all appears to be aimed at the latter and we have really struggled to find anything to help with what we are going through. We've ended up feeling isolated from our own 'MS Community' because we just don't fit in.

My husband has 6 weekly catheter changes that are done by the community nurses as he is incontinent, and sadly he is showing signs of becoming doubly incontinent as he is struggling to control his bowel movements.

One of the main things I've noticed is how little support there is for myself, as an unpaid carer. Medical professionals, friends and family all concentrate on my husband and neglect to see how I am doing. I am the one that is keeping him going and caring for him and keeping him out of hospital, but I am never checked on or acknowledged. If I go down, then they have a big problem on their hands but that doesn't seem to occur to them. My husband only engages with healthcare services because I physically take him there, as far as he is concerned, they can't cure his diagnosis so what is the point of going to see them, yet when I am at his appointments with him, I am ignored and not listened to. I advocate for him but who advocates for me?

There is always a lot of talk surrounding 'Safeguarding' when it comes to patients and unpaid carers and usually it is focusing on the patient, but actually at what point does the safety of the one doing the caring become an issue? I was recently asked at a routine GP appointment if I "felt safe at home? Was I experiencing any signs of domestic abuse?" and when I answered honestly and said I didn't feel safe at home because of what I do for my husband and his condition I was told "oh no sorry we don't mean that, we just need to tick a box for domestic abuse". Just because I'm not being physically or mentally abused by my husband doesn't *mean I don't get to feel unsafe in my home or environment.*

He is registered housebound so is supposed to have home visits where possible for podiatry etc but cuts have been made are these routine visits are no longer an option. They will only come to see him if he has a visible open wound, but by that point he could be in a position where he needs a hospital admission due to the severity of it. Having a carer at home is seen as a solution but as carers we aren't trained to do anything so how should we suddenly know how to do things that services like podiatry have trained for?

I rarely reach out for help, and if I do it is usually because I am crisis point and keeping a sinking sink afloat with the life raft, and its usually the MS nurses that I go to. I am always faced with an answerphone then a 3-4 day wait to get a reply, by which point it is usually too late. If I am asking for help it's because I need it now, not later.

If he is admitted to hospital then he is a massive strain on them, him being there would involve a huge care package and the use of a lot of time and resources when they are already stretched. It is better for everyone if he stays out of hospital and at home so why are they not putting the support and provisions in place to keep it that way?

Before moving down to Devon, we lived in Dorset and we were entitled to a £300 Yearly fund to be used as respite for the unpaid carers, this amount gave me 1 night away every 6 months and it was what kept me going when thigs got really tough. That has since been scrapped because of funding cuts and now we're left with no even consideration of being eligible for care or a care package because we have savings.

I just wish that more focus could be given to the unpaid carers in this world, because without them the NHS would be even more flooded. Us carers are a preventative measure in our own right so why can't we be protected as one?!

On a side note- the community nurses that come to see us are absolutely, bloody brilliant!!! If I ring them for help or advice or a visit then they come that same day, or they call back within a few hours! They see the situation we are in so they understand, they feel it! Throughout his diagnosis we saw an array of medical professional from neurological consultants to registrars and without a doubt the community nurses we have are ahead of them all! They deserve every gold medal I could give them!"

STORY 36: Chagford Memory and Community Café 12th May 2023

Person A is a carer for her father. She was not able to find a nursing home in the area. There used to be two nursing homes in Chagford which had both closed down and the nursing home in Mortonhampstead did not have any space available. She believes that the nursing homes in Chagford had closed down due to new rules that require an en suite for each room. It was not possible for the care homes to make this financially viable and so they closed. It's very difficult to get carers in the area and she relies on agency staff which charge a lot of money. She does not believe that agency staff are treated well by the agency.

STORY 37: Chagford Memory and Community Café 12th May 2023

Person B had been living abroad in Mauritius but had to return home to care for her elderly mother. Her father had died several years before and the carer who had been looking after him was able to stay on to care for her mother. The carer reported that her mother had become increasingly confused and disorientated. He decided to take her to hospital and after checking her they would not allow her to leave without a care plan in place. As there were no care homes in Chagford Person B returned to England to take care of her mother. She's able to afford carers from 10 – 1 and looks after her mother in the weekend and afternoons.

She finds it very difficult to organize the different tablets that have mother must take which were prescribed to her after her hospital visit. She said in comparison to her experience living abroad, where elderly and frail people were taken in with the family, she finds that care in England is limited and poor quality.

STORY 38: Chagford Memory and Community Café 12th May 2023

Person C is a carer for his mother. He has been caring for her for two years as she suffers from dementia. He was able to find a house opposite them for his mother to live in. He said it was cheaper to find live-in carers than to put her in a care home.

He believes that no one should be put in the position to have to sell a house to afford care for a loved one. He said, *"what's the difference between dementia and falling over and breaking your leg? Why should one be penalized? Care is left to the dependents – if the person has any. My mother would be horrified to know we had to sell her house and give away her belongings."*

STORY 39: Chagford Memory and Community Café 12th May 2023

Person E was a carer for her husband who had Alzheimer's. They were not able to find a care home for him in the area and the nearest available care home available was in Paignton. She would visit him during the week and would stay in the care home sleeping in a chair.

When she returned home on s Sunday night to sleep at her own home, she was informed that he had died early on Monday morning. It was very distressing not to be able to be there on his final hours. Her home is half a mile away from Mortonhampstead Hospital. She was very frustrated that the hospital had closed. She said 'I can't understand why they're closing hospitals. It is so important to have good palliative care. When they came to ask us about the closing of the hospital, everybody said how important it was that they weren't interested. They were going to close it whatever we said.

There should be much more work done to help people to stay in their own homes. The best option would be to stay at home with home help and the next best option is a local Cottage Hospital.

STORY 40: Chagford Memory and Community Café 12th May 2023

Person H talked about a pendant alarm that her father had been paying for 12 years for his wife. The pendant alarm was managed by the District Council. He decided to test the batteries and found out that the batteries had run out. When he contacted the District Council, they told him that they had received a low battery alert but didn't tell the family as they needed to receive 3 low battery alerts before they contacted the family. The alarm cost 45 pounds a quarter and he had been paying for it for 12 years. He did not know how long it hadn't been working for but was offered a small refund.

After he initially complained he felt he was fobbed off so escalated the complaint. At this point they sent him the frequently asked questions which highlighted that you should test your alarm regularly. He had not seen these at any point in the 12 years.

She said that it was possible to buy a replacement pendant alarm online for £10 but that the District Council charged £60 for a replacement alarm. She said that her father had been initially asked for three local contacts that the Monitoring Centre could contact if the alarm was set off before contacting the Emergency Services. After reading the FAQs her father checked these contacts and realised that they were very out of date as they had been carried out 12 years before. One of the contacts was now 95 years old.

She said “*people get these pendant alarms for peace of mind. They need them when they’re most vulnerable. This service really let us down. Next time we would go with a commercial company rather than with the district council. The Monitoring Centre is manned by one person. What happens when that person goes on holiday or is not available. This is a safeguarding issue.*”

Primary Care - Dentistry Services

STORY 41: One resident has lived here for nearly 6 years and still has no dentist because nowhere locally has any NHS availability and they cannot afford the cost of going private.

STORY 42: “*My experience of setting up health provision for Kateryna is that once the Ukrainian person has obtained their biometric identity card (which is easy if she has a UK address) it is very easy to register with the Health Centre. Finding Kateryna a dentist has been problematic, in fact impossible. The recommendation is that she go to A & E for any emergency dental treatment*”.

STORY 43: (Moretonhampstead) - Patient had an initial appointment for a filling and was then told I needed root canal. After two further appointments for failed attempts at the treatment I was told, I would need to pay and go private to see a specialist. I did so and had an initial consultation to which I was shown X-Rays and told that in fact I’d had no root canal treatment done or even attempted and instead whatever procedure they had attempted to do had resulted in the growth of a large abscess and severe amounts of pain.

STORY 44: “*I’ve had a long history of getting help and support from the NHS. Back in 1998 I became ill, struggling with energy so low I found it difficult to climb stairs. I went to my GP, but they weren’t very supportive. Initial tests didn’t show anything, and the GP felt I was making things up. I was self-employed at the time and couldn’t afford to take time off work. Eventually I saw a newly qualified locum GP and was diagnosed M.E. At the time there was no treatment so I had no choice but to carry on as best as possible. I also had poor response to treatment for asthma and hay fever.*

When I saw a nutritionist, I was diagnosed with “Adrenal Exhaustion” and changed my diet to be more animal protein based things started to improve. I decided to look into more alternative therapies. Unfortunately, many alternative therapies are not available on the NHS, or are limited in the number of sessions you can have. They just start to work and you have to stop because your sessions are up.

As M.E support improved, I was seen by an M.E. specialist in Exeter and I became involved in a pain management group run by the psychology team. From this I discovered than my condition was down to PTSD

brought on my childhood abuse. It was a good support group and we continued to meet as a group of friends for about a year afterwards.

I was also seen by a consultant, though this was not a great experience. They were late to my appointment and not interested in what I had to say. I was placed on SSRIs which are very strong drugs with side effects and caused suicidal thoughts, I refused them. I don't have an issue with conventional medicine, they just don't work for me.

In addition to the medical side of the NHS I've also struggled with NHS dentistry. I needed a tooth extraction but there were waiting lists for NHS dentists. I was in so much pain I had no choice but to go private.

My current GP is fantastic, I have no complaints, they are fantastic. Very efficient and no problems with getting appointments."

STORY 45: Mr E (Ilfracombe) - This gentleman is now in his 70s and he has been very active in local government and that includes sitting on the board for the local District Hospital. (I have included this information because Mr E knows the NHS 'system' and his way around it.) I don't think he does this work anymore. He has had problems locating a dentist. His speech difficulty is due to pain and having only one remaining tooth.

He appears to be a private man and is proud of the work that he done in the past, in local government, and the hospital. And she seemed to be very disappointed in the way that things were moving. He was able to tell me quite a bit about what he thought was happening in the background and where hospital and domiciliary services cut back. To gain his trust I briefly told him of my difficulties in trying to get a dentist. Understandably, he feels disloyal making complaints of a hard pressed service. He has a friend who helps him.

With transport and communication problems (difficulty talking on the phone) but getting a dentist in the southwest of the United Kingdom has been an impossibility. And I know this from colleagues of mine who work at the host organization rang around every single dentist in the west country, and none of them were taking on national health patients. Mr E feels that he has been very responsible about his oral health in the past.

When it came to finding making an appointment for the dentist, he found that he was no longer on the list. It transpired that he was unable to go to the dentist (during COVID) because he was advised that because of the other health problems they had (which I did not explore with him and he didn't want to reveal). He stuck to the 'rules' and he now finds that he has been struck off the list for non-attendance for 2 years. Now this could be because he didn't keep in touch with them, but this is clearly a very intelligent gentleman, who knows about health services, and he was not informed that he had to do this. He was of the mind that he would stay on the NH dentist list. And you visit them every two years wherever you can. And the fact that COVID has struck, it's not really his problem or his fault.

He's very embarrassed about his speaking and clearly, he has to have somebody to help him in that way. He feels disempowered. So, we are left with the situation where we have to find a dentist for him. After this interview, we went back to the computers at the Candar Centre, which is where Encompass (the host organisation) works from, and we went through the various University Hospitals, such as Plymouth and Exeter and Bristol. And even further afield. (Much of my work as a Core 20+ CoOrd is trying to tackle the issues raised by the narratives.)

STORY 46: Core 20 +5 Focus Group Moretonhampstead Community Hall. 24th February 2023.

P: states her firm support for the NHS but navigating it to access services, particularly dentist registration, can be far too bureaucratic and overwhelming. It's easier to go private.

There was a discussion about the demise of NHS dental services and concern about the impact on children's dental health.

Primary Care - Social Prescribing/Connecting Services

STORY 47: Core 20 +5 Focus Group Moretonhampstead Community Hall 24th february 2023

We discussed the possibility of 'community link' organisations providing help and support for form-filling, shopping, general buddying. Becky Beesley, Moretonhampstead's community social prescriber, is a crucial figure in this respect, and Wellmoor is the type of community organisation that can be a vehicle for these small but significant connecting support mechanisms.

There is a discussion about the dependency health services have on volunteers filling the gaps, and the difficulty of recruiting and retaining these volunteers since COVID, but also how the cost-of-living crisis has hit the capacity of people to find the time to perform work without pay. Previously volunteers would donate petrol costs when using cars for volunteer work, but this is increasingly less often the case.

Secondary Care - Hospital Services

STORY 48: Mr W (Ilfracombe) was diagnosed with a malignant growth in his colon at the North Devon District Hospital. He was scheduled to have an end-to-end anastomosis in Cheltenham hospital in December 2022.A problem with transportation arose since Cheltenham is far from North Devon (144 miles / 2 h 32 min), and Mr. W refused sedation for his initial colonoscopy and caught the bus.Mr. W was transferred from one hospital to another that is far away and had transportation problems, making it difficult for him to board a bus and travel to his own operation on time for 7:30 in the morning. However, he was able to arrange transportation through the council transportation service supported by the Ilfracombe Centre. His two daughters live in the Wirral, where Mr. W is originally from, and he claimed that they were too far away for him to arrange transport with them. His son is self-employed and Mr W felt that the hospital may have assumed that the transportation would be up to him. The discharge nurse may have assumed that Mr. W would be able to provide transport, but he did not communicate this to them.

Mr. W had been in a car accident 20 years earlier, and when he went to see his doctor, he mentioned that he had been having nightmares. Doctors may not understand how stress can affect symptoms

of PTSD, or there may be a reluctance to go further due to poor communication, lack of medical education, or logistic problems. I saw Mr. W again when he called into the Candar (Encompass) Centre and I helped him complete his request for reimbursement for transport costs. The cost was £150 for a round trip to Cheltenham. Mr W has had another journey to Cheltenham to have a colonoscopy. Mr W had a bowel resection last December and his follow-ups are also now at Cheltenham. I (Core20+ CoOrd) assisted him with his travel claim form; another reimbursement of £150. Mr W has to pay this amount up front to collect a receipt before getting reimbursed. He can afford to do this. There is an endoscopy department (Gemini Unit) at NDDH in Barnstaple.

STORY 49: Mr O (Ilfracombe) is a. 65 year old man recently diagnosed with prostate cancer. He had originally undergone hormone treatment which involves the injection of female hormones. This lowered his libido and reduced the size of his testes. It seems that Mr O had a brief introduction to this and no counselling was offered. He was given a list of people he could ring who had had a similar operation or procedure. He could contact them if he wanted any advice or help. After the hormone therapy he was then due to have radiotherapy, which was directed at his groin area. He also had a coexisting inguinal hernia and he was told that he would experience diarrhoea and stomach cramps with the radiotherapy and that the inguinal hernia would exacerbate this. However, if he went on the waiting list to have this hernia repair, by the time he got to the top of the list, it might have been too late for the radiotherapy for his prostate cancer, with the obvious conclusion. This left Mr. O with no alternative but to pay privately to have an inguinal hernia repair. Fortunately, he was able to do this, and one wonders what would happen if he had not got the money. For some reason the radiotherapy is now located in Exeter which is 66 miles away from where he lives, and because of the side effects of the radiotherapy, it means that he requires the use of the toilet frequently and without warning. Unfortunately, it was not a case of using the facilities at the next services because the side effects come on almost immediately and without warning. Mr O resorted to asking his taxi driver to stop and using a bush as a toilet.

STORY 50: I joined the end of a local HOPE course focused on “Chronic pain, Fibromyalgia, ME and Long Covid” and asked the group of 6 participants if they had a direct experience of health inequalities. Below is an outline of their responses and the conversations it provoked:

“I had a haematology appointment at the R D and E, during which I needed a blood test taking. Rather than having the blood taken at the haematology unit I was expected to walk to the other end of the hospital and wait for a blood test to be taken for the results to then be sent back to my original haematology appointment. I have limited mobility and rely on the sue of 2 sticks to walk so the distance I was expected to travel left me in inconsiderable amounts of pain. I feel like this is a situation that could have been totally avoided if services had spoken to each other and been more streamline in their treatments.”

“After I eventually managed to get an appointment with my GP it was a telephone consultation. After describing the symptoms I had been suffering with for a while they decided that it was due to depression and prescribed with me antidepressants. I wasn’t happy with this diagnosed and requested another appointment, unsurprisingly it was another telephone call but this time luckily the doctor on the end of the phone actual listened to me and my symptoms, advised me to stop taking the antidepressants immediately (I hadn’t started them thankfully) and treated me for Long Covid. If I had listened to the first doctor I spoke to I would still be undiagnosed and taking unnecessary medication. I feel if appointments weren’t always over the phone then this situation could

have been avoided"

"It took me over 8 years and 2 doctor changes to get a diagnosis. I felt like I wasn't listened to or acknowledged due to my age and past medical history. The GP was blaming all new symptoms on my pre-existing mental health issues rather than treating it as a new problem, they were blinkered to their own diagnosis and not open to other ideas. This meant I was undiagnosed for an extremely long period of time and my lifestyle etc was compromised as a result"

"There needs to be more awareness locally of the courses available like this one (HOPE course). I was only made aware because my GP mentioned it, before then I had never heard of anything like that being available. It could help many people if they knew about it."

"As a room full of individuals that suffer with multiple disorders or diagnosis a simple 5-minute GP appointment isn't enough. Could there not be a possibility of making a weekly or monthly dedicated day to sufferers of multiple illnesses with extended GP appointment slots so we are able to discuss all our complaints rather than having to treat just one each time?"

Another individual in the room felt that the GP she saw had already diagnosed her problems as being because of her weight, as a result of this she lost 7 stone to be considered as something other than "overweight" and actually have her health ailments looked into.

The common theme amongst the group was very much aimed at their local GP surgeries and the care they receive. They felt like enough time isn't given at appointments, there isn't enough support for individuals like themselves that have multiple health complaints, they aren't strong enough to challenge a doctors opinion or diagnosis it they disagreed with it- they suggested a role being put in place for this, a potential "patient advocate"- and that the E-Consult and telephone appointment system was ineffective when treating their conditions, suggesting instead that initial contact could be a telephone then any subsequent appointments should be in person.

STORY 51: Older man (North Dartmoor). Routine blood test points to anaemia. Referral to acute hospital / consultation with prescribed 6 weeks / colonoscopy shows malignant bowel cancer tumours / surgery within another 6 weeks / results clear, so no follow up treatment needed other than regular monitoring. Pleased with process/ outcome.

STORY 52: We met this Lady frantic at a bus stop (North Dartmoor). Scheduled bus didn't arrive. She was waiting for it as transport to hospital appointment. Bus not arriving meant she missed her appointment with the cancer specialists. No other ways or means of getting to hospital so she is now at a disadvantage as she can no longer access the vital services she needs.

STORY 53: Woman (North Dartmoor). "After over eight years of red, sore ears and other cartilage inflammation I was diagnosed with Relapsing Polychondritis by the top professor in the UK. All local services failed. Joint pain has affected me for most of my life. During lockdown my condition attacked my breathing causing a rare complication Tracheobronchomalacia. I'm also affected by endometriosis, coronary artery spasm, coccydynia, and now a cecal volvulus causing significant pain and problems.

Previously I was an avid walker and sporty woman. Now I have accepted and adapted to life's changes and use mobility equipment and aids to remain as independent as possible. My writing, arts, crafts and music have brought solace and pacing helps me to be positive. I wish for a future of joined up thinking where multi-disciplinary teams are everywhere with the patient first. There is a huge difference between local care, and city care with surveys ensuring patient led respect is held. Unfortunately, this is lacking elsewhere. Self-advocacy is so tiring and fighting to be believed triggers bad mental health. Please reach out for support from people when you're too fatigued to fight alone."

Care coordination

"Without my city team I would be lost. Primarily I am under the care of Guy's and St Thomas' Hospital in London, though I live in Devon. My local rheumatologist in Exeter sees me about once a year. I also had to change my local rheumatologist as she advised she wanted me to stop my medication to prove my condition. So all my treatment comes from London, that is where the specialists in my condition are. I now have mainly telephone appointments with London then if I have a scan or appointment in another London department my rheumatologist will coordinate with me so I can see multiple people on one trip."

Attempting to coordinate locally

"I developed Tracheobronchomalacia as a result of Relapsing Polychondritis. I was waiting to be seen locally for this, the team in London were hoping to work with Exeter. After low Sats I was admitted to Exeter hospital where I was told I was wasting bed space and time and shouldn't be there, by a consultant. I had to complain and get in touch with London in order to receive any help. Now my care for this is managed purely from St Thomas' in London.

Now I have developed a mobile cecum. After this new diagnosis I was discharged with no advice locally. Therefore, I am being treated by St Thomas' in London for this too after. It would be so much better if coordination was created. There is little coordination at present. My London rheumatologist is excellent and treats me with respect. I feel believed and valued. But I'm frightened to reach out locally for fear of being ignored. There are many times I am alone, in pain and in need of help when I daren't call an ambulance."

A few negative examples

Blood tests: "*I have to have blood tests every three months. If I have any at Exeter hospital they are not able to send results to London due to their system. Every time I have to have tests with my GP and get asked questions as my drugs are not on repeat prescription because they come from London. The GP then emails them to London.*

Don't fit the box: I have an inhaler and peak flow meter for my Tracheobronchomalacia. My GP put me on the long-term condition monitoring list at my surgery which really helped for a few months. Being able to check in, instead of developing a list of problems was very positive. Then another person took me off the list because I don't have asthma – I don't tick the box to allow me to be on the list as my condition is rare, so now I'm back to not being monitored at all locally.

Parting words: I am so fed up with how medical professionals can ask for respect and courtesy yet often don't reciprocate. No wonder there is frustration. I was ignored and fobbed off for 18 years before my endometriosis diagnosis and feel the system is still the same now in many areas. I was on holiday last year and had an infection which I have rescue antibiotics for, so I took them as I have already had sepsis once. On return I tried to refill my antibiotics and was rudely told I could not have anymore as I had 'blatantly abused them'. I had been taking the same antibiotics for the same type of infections for *over 5 years on GP advice. I argued this and they were prescribed. It's so upsetting to follow guidance then be told it doesn't apply anymore and be blamed. On a positive note my GP practice has followed London's example in recent weeks with a survey by text after appointments. People must be encouraged to fill these in, it only takes a few minutes. This is my personal account, although as a Covid story, technically it doesn't fall into the remit. But anyway, I submit it, anonymously of course, as a contribution if at all useful."*

STORY 54: *"I had an eye examination at RD&E during which it was suggested that photos would be sent to Liverpool for their opinion. A couple of weeks later I received a text from 'Opthalmic Oncology' at Liverpool offering me a consultation. This was the first time I was aware of cancer as a possible diagnosis – it was quite a shock. I was unable to attend this appointment (on Dec. 19th) because of the short notice and the need to make arrangements to be away from home. This wasn't totally Liverpool's fault. Information had been mailed to me but had not been delivered because of the postal strike at the time. An appointment was offered for January 9th which I accepted.*

You are always requested not to drive when attending eye appointments so as I had no one local to accompany me, I used public transport. This involved local bus Moreton to Exeter, National Express Exeter to Birmingham then National Express Birmingham to Liverpool followed by taxi to hotel. The overnight stay prior to the appointment was covered by NHS.

The examinations etc. at Liverpool were very thorough and their diagnosis was that it was not melanoma – a relief! I then had to do the reverse journey home. I realised that if I tried to travel back on the day of the consultation, I would arrive in Exeter late at night with no way to get to Moreton so I stayed a second night and began the journey back early the following day to get to Exeter in time to get a local bus home.

Whilst I am very grateful for being seen, I think that more could have been done to make me aware of the possible outcome rather than just to be met with 'Opthalmic Oncology' as the heading to a text. This really worried me and I spent the whole of Christmas in a bit of a state.

I am quite capable of making travel arrangements and travelling alone, I did it a lot when working, but it occurred to me that for many this would be difficult, not to mention expensive. There was no discussion about how or if I could manage. This exercise brought home to me that living in a rural area does sometimes have its disadvantages particularly if you live alone. It's getting to the major sources of public transport that make it more difficult, particularly when having to travel on a Sunday.

I must emphasise that I am grateful to the NHS for the professional aspects of the treatment but I do think there needs to be better communication when asking patients to travel long distances."

STORY 55: One gentleman told of the time he fell whilst on his way home from work. He was advised to go to a hospital over 28 miles away. He is unable to drive and as it was evening time there was no public transport available so he was left with no option but to wait overnight in significant pain and go to a closer walk-in centre the following morning that was accessible via the limited offerings of public transport available.

STORY 56: One woman had to again travel over 100 miles there and back for a procedure that could not be performed at the local community hospital due to there being no doctors based there. As she doesn't drive she had to ask someone else to take her which resulted in them having to take a day off work to do so. The same woman also said previously she had to go to A and E for what was deemed by the GP to be a matter of emergency. She explained she had no means of getting there to which she was told by the medical centre that *"they had tried the ambulance service but none are available for over 20 hours so go out on the road and flag a car down, someone will have to take you!"* She later received an apology for these comments after a formal complaint.

STORY 57: Public transport was repeatedly a highlighted issue as there is no direct bus route to the main hospitals so a routine hospital appointment could add additional hours to your trip with numerous bus stop changes and a lengthy walk.

STORY 58: *"Mrs W (Black Torrington) aged 80 was taken to North Devon Hospital on 3rd Feb due to a chest infection. She was very poorly and put on gas and air. Her asthma and breathing were scary to see. She made progress but extremely weak. On Friday 10th they came to her and said she was going home that day. Living alone she said she did not think she had the energy to go home but basically, they told her that was her problem not theirs. She was very frightened and upset and didn't know how she was going to get home. They put her in a taxi in the end. If only we had Holsworthy hospital or Okehampton hospital open to help people in these situations. 5 days to have some rehabilitation would be the answer to all the bed blocking and reassuring to the patients."* An account from the relative of Mrs W, a resident of the remote village of Black Torrington.

STORY 59: One lady told us how she had to call 111 on behalf of some Ukrainian friends and even accompany them to Exeter A & E as there were no interpretation services available.

STORY 60: M, 68. (Male) Born in Bovey Tracey, 37 years in Moretonhampstead, and happy to stay in the village. Sons are nearby (Exmouth) and call regularly. Wife died last November (2022), and M was her main carer during her illness whilst he himself was also ill. M is a registered Devon carer, having worked at Coppelia House care home in Moretonhampstead as a cleaner, chef and carer for several years. His son also worked there and now manages a care home.

Whilst caring for his wife full-time, M applied for a carers allowance but was refused, and just about coped financially. M's own health problems started in January 2020. He felt a sharp pain in his side and after three days of pain he saw his GP at the Moretonhampstead health centre. The GP acted quickly and sent him by local ambulance to Exeter RD&E. His wife accompanied him. After an hour's wait, M was given a series of tests and received an immediate diagnosis of bowel cancer, and two weeks later had an operation to remove the tumour and now has a stoma surgically inserted for the rest of his life. In March of 2022 a subsequent lymph node removal operation went well.

M says his care from both Moretonhampstead Health centre and RD&E was excellent, with good clear communication and quick responses. His ward experience was also good. He has check-ups every six months (including CT and MRI scans) and makes use of the Moor Care car service which is £12.00 for a round trip between Moretonhampstead and Exeter. He prefers this to the public bus service.

Whilst in recovery and during the COVID lockdown his wife became seriously ill. Initially some agency carers from Wales were dispatched for daily visits, and then local carers were sent. PPE was worn and social distancing observed. M is unclear how this care support was commissioned. When the care support stopped M took care of his wife by himself with some help from his son. He administered his wife's' medication.

Today is an important day as M has been given the all-clear.

STORY 61: *"I've had a long history of getting help and support from the NHS. Back in 1998 I became ill, struggling with energy so low I found it difficult to climb stairs. I went to my GP, but they weren't very supportive. Initial tests didn't show anything, and the GP felt I was making things up. I was self-employed at the time and couldn't afford to take time off work. Eventually I saw a newly qualified locum GP and was diagnosed M.E. At the time there was no treatment so I had no choice but to carry on as best as possible. I also had poor response to treatment for asthma and hay fever.*

When I saw a nutritionist, I was diagnosed with "Adrenal Exhaustion" and changed my diet to be more animal protein based things started to improve. I decided to look into more alternative therapies. Unfortunately, many alternative therapies are not available on the NHS, or are limited in the number of sessions you can have. They just start to work and you have to stop because your sessions are up.

As M.E support improved, I was seen by an M.E. specialist in Exeter and I became involved in a pain management group run by the psychology team. From this I discovered than my condition was down to PTSD brought on my childhood abuse. It was a good support group and we continued to meet as a group of friends for about a year afterwards.

I was also seen by a consultant, though this was not a great experience. They were late to my appointment and not interested in what I had to say. I was placed on SSRIs which are very strong drugs with side effects and caused suicidal thoughts, I refused them. I don't have an issue with conventional medicine, they just don't work for me.

In addition to the medical side of the NHS I've also struggled with NHS dentistry. I needed a tooth extraction but there were waiting lists for NHS dentists. I was in so much pain I had no choice but to go private.

My current GP is fantastic, I have no complaints, they are fantastic. Very efficient and no problems with getting appointments."

STORY 62: Chagford Memory and Community Café 12th May 2023

Person I talked about her father who was discharged from hospital while she was away. He was waiting in the discharge area for hours. He was told by the hospital that there were no community drivers available. The distance from the hospital to his home as 20 miles. Her father is a carer for her mother who was blind with advanced Alzheimer's and is also losing her hearing.

He was not willing to pay for a taxi. She said *"in that generation they don't want to spend money on something like a taxi. He is of a generation where you save up for a rainy day. It was just luck that somebody was able to pick him up from our family. He had been there for hours."*

STORY 63: Chagford Memory and Community Café 12th May 2023

Person L said that they were very lucky in Chagford as it was possible to get an appointment with the doctors' surgery quite easily. She said that the main problem they were finding was with getting hospital appointments. As she does not drive, she relies upon the local charity Morecare to take her to hospital visits. This is a voluntary service, but they do ask for a donation. She said that it would cost around 10 pounds to take somebody to Okehampton. Sometimes she would have appointments twice a week and £20 pounds was more than she could afford.

She said public transport was very limited and if you were missed the bus on the way home you would be stuck in Exeter. In Exeter you also have to change buses at this bus station to be able to reach the hospital which is complicated and time consuming.

STORY 64: Chagford Memory and Community Café 12th May 2023

Person M said that the main problem with living in a rural area was getting transportation to hospitals. It was possible to get a lift through people in the community. She has a problem with her hips and is not able to walk very far.

She said *"the worst thing is if the hospital calls up to say that there's been a cancellation you could be seen earlier but can't organise a trip at short notice. With petrol prices increasing it's getting harder and harder for community groups to pay for this transport and it involves the volunteer waiting a long time at the hospital."*

STORY 65: Mr S (Ilfracombe) who is 19 years old has been complaining of chest pain for several months. He has repeatedly gone to the hospital and been given an ECG when his GP has asked him to go and get a chest x-ray. He has repeated ECGs which are all normal but the hospital does not then proceed to a chest x ray. Mr S was not a particularly good historian and it was unclear whether the GP had written a request note for the x ray department to undertake a CXR because they are unlikely to do so without a formal request from his GP. However, I have included this narrative because no one has picked up (so it seems) that Mr S fits the physical profile of young fit and tall healthy males who suddenly die for no apparent reason.

STORY 66: Focus Group Moretonhampstead Community Hall, 24th February 2023

R: 3 to 4 years ago he felt 'weedy'. Visited Moretonhampstead GP, had blood tests, showed signs of anaemia. GP quickly referred him on to the gastroenterology unit at Exeter RD&E. R says the 'not knowing' was the scariest thing. Anaemia is linked to bowel cancer. He saw a consultant at Exeter RD&E, had tests, and ultimately an operation. It was bowel cancer but he was fine, as it was caught in time, thankfully. But it was pure chance that it was discovered.

R talks about the good and bad experiences of being in the hospital, seeing people on trolleys, the food... His treatment was generally good, despite gaps in communication. The nurses were good, the consultants were a bit aloof, somewhat indifferent, talking over his head sometimes. Now R is fully recovered.

Some general comments were made that the hardest part is often getting an appointment. Once an appointment has been obtained the GPs are generally good. It's a pity that the hospital in Moretonhampstead no longer exists. The closure has been a big loss, we agree, as are all the many closures of local hospitals and healthcare services throughout the locale. These losses are deeply felt.

Secondary Care - Emergency Services

STORY 67: Chagford Memory and Community Café 12th May 2023

Person K's husband had died just before Christmas. He had suffered from COPD and it had lots of coughs in the past few months. The only time he had ever complained about it was in the week before he died. On the Saturday she was worried about his health. They had decided to go to the doctors on Monday but he had been getting worse. She called 111 on Saturday evening and the person she spoke to said she should expect a call back within two to three hours. She did not hear back despite waiting up through the night. She finally received a call back on Sunday morning. The person explained that due to a server issue they had lost her call and apologized.

She said she had not wanted to call 999 because of the campaign urging people not to use it unless it was urgent. She also did not want to tie up the line by calling it 999 when she was expecting a call back from the 111 team. In the end, she called 999 on her mobile phone. As she was calling 999, the 111 ranked number rang back and said that she would need an ambulance. Her husband was taken to hospital on Sunday night. When he arrived at hospital, they told her that it was too late. He had advanced pneumonia and died at 6.20am on Monday.

She was told that if he had become into hospital earlier there was a chance that he would have survived with the antibiotics. Her husband was 82 years old when he died. Person K was extremely upset and felt responsible for not calling 999 quicker. She said he had been trembling and she didn't realise how serious it was without someone to talk to.

STORY 68: Focus Group Moretonhampstead Community Hall. 24th February 2023

C1: Describes the tragic circumstances 8 years ago of missing her sons' wedding in S. Africa because her father died on the day, she left for the airport to fly there. She comments how she has barely seen all her adult children since that event, and this appears to weigh on her. She has been a heavy smoker and has given up. Her sister is around to 'get on her case' about that.

Last week C called the ambulance after a fall (suffering from pneumonia..?). The First Responders were quickly on the scene, then the fire service, and then an ambulance came to take her to Exeter. Once at the RD&E she was on a trolley outside the A+E for 7 hours. She was wheezy. She did get fed; the food was good. She stayed on ward. At some point she fell down again whilst visiting the toilet and couldn't breathe properly. She was moved to ITU. Did she get an aftercare? *"I look after myself."*

Digital Inclusion

STORY 69: Female (Hatherleigh) - Starting from being completely illiterate when it came to her technology, this client received multiple sessions over a prolonged number of months in order to help her feel more confident and to understand how best her iPad and phone could help her in her everyday life. Focusing on some key skills which would help her to connect with friends and family better, this client learnt things such as how to text, email and use Facebook, all of which enabled her to more easily and frequently stay in contact with people, particularly her children who did not live close by, which she was enormously thankful for and greatly improved her wellbeing. These skills also enabled

her to be more independent, and she was even able to contact bill providers over email when needed, as well as search the internet for information instead of having to always rely on others – this meant she was able to do things like look at websites for her local garden centre and see their stock and opening times, providing her with a new sense of independence thanks to her technology.

STORY 70: Female (Moretonhampstead) - This client had always loved a gadget and was fairly good at using her mobile and tablet, however, did have multiple questions which she felt would enable her to use these items to their full potential. For example, we discussed password safety and introduced the idea of an authenticator app to help her feel less stressed over both the safety aspect as well as the pressure to memorise so many different passwords, as this was something which was impacting her massively. This client was also trying to use YouTube to follow small fitness and breathing exercises to improve her health and mobility, but found it extremely frustrating to re-find the videos she'd enjoyed once the app had been closed and reopened; therefore, we introduced her to the idea of playlists on YouTube, allowing her to save the videos she found helpful in one simple place to reuse at a later date, thereby encouraging her to do them more often and improve her health in the process of using her technology.

STORY 71: Male (Moretonhampstead) - This client was a complete technology novice, and had some issues with memory, so we focused on repeating a very small number of tasks over a couple of sessions until he felt he was improving. Primarily, due to living far away from family and therefore to negate any isolation which would stem from this, throughout our time we focused on this client being able to use his phone as a means of staying in contact more easily and more frequently with his family members. Therefore, the main activity was to teach this client how to use Whatsapp – this was what most of his family used to communicate and was a specific request from his daughter as to what it would be useful for him to learn. Through learning this, this client was able to send messages to his family to keep in touch more often as opposed to only speaking to them during more infrequent phone calls. This also meant he could see photos that they would send him, which made him overjoyed, particularly to see those of his grandchildren, all of which improved his wellbeing by making him feel more connected to his family despite the distance between them.

STORY 72: Whilst at the Mental Health Workshop that was held in Okehampton on 9th May we spoke about the impact that digital services and connection issues have for individuals in rural towns and villages like those populated in the 4 areas covered in North Dartmoor- Okehampton, Chagford, Black Torrington and Moretonhampstead.

We spoke about how people who live in the even more remote villages with little to no signal or internet connection are automatically excluded from new systems put in place for accessing healthcare services- e.g., online doctors consultations, repeat prescription services, alternatives to 111.

Whilst on this subject it also occurred to us as a collective that not only are they at a disadvantage when trying to access the services needed, they are also at a disadvantage when getting information about the services on offer. Most groups/services on offer are advertised through the means of social media or doctors' websites, but for people who don't have access to these sites due to personal reasons or connection issues then they have no means of seeing what help is available.

There needs to be a solution to bridge the gap and give everyone the fair access to services on offer. They may not need them, use them or be interested in them but they have the right to fair healthcare and all it entails.

Moretonhampstead Ukraine Group Testimony

STORY 73: *"A few thoughts relevant to your topic that have come us during my role as Day Tripper Leader are:*

- People of a senior age, living with either mental (dementia etc.) or physical difficulties (e.g. mobility) struggle more with a sense of isolation particularly if they live alone or have not got family nearby to act on their behalf.

- Organisations such as Moorcare who help provide transport to much needed doctors/ hospital appointments are invaluable but insecure as they are run by volunteers who are not always available.

- Organisation such as Wellmoor who provide social, therapeutic and travel opportunities for senior people living in a rural setting are very much appreciated and valued as they foster a sense of connection to the community and the nearby geographic area.

- The main barrier to healthcare is the limitation of the provision: my observation is that this project has definitely improved the quality of life for a lot of people (both mentally, physically and emotionally). The people who have benefited are not only the participants but also the younger volunteers from all backgrounds. There is undoubtedly a demand for a continuation of these sessions".

Moretonhampstead Memory Café 27th April 2023

STORY 74:

Click here for interview 1

Click here for interview 2

Community Connector Co-ordinator Testimony

STORY 75: Co-ordinator: In the North Dartmoor PCN area, an emergent theme is based on the maternity services, or lack of. Case studies have been put together of women who experienced positive births and had no problems with delivery of service at the RD&E, but received limited prenatal care (i.e. antenatal classes, breast feeding sessions) and postnatal services. The coordinator is aware that a large percentage of stories collected so far are outside of the Core 20+5 but thinks it's important to remember the point of this project- to hear from people on the ground the problems they have faced and deemed as a “health inequality”. The project cannot be treated as a “one size fits all” and only focus on what the research beforehand has highlighted because every person, group and locality differs so massively. It’s becoming apparent through doing this project that actually the inequalities faced in the NDPCN area are not at face value “health inequalities” they are in fact service inequalities that then have a knock-on effect and become health inequalities. It seems unfair to discount the voices being heard and stories being told just because they do not fit in with the Core 20 targets. If local hospital closures, limited public transport and unreliable pharmacy facilities are stopping people accessing a vital service they need then that is what should be highlighted to the project leads. People aren’t viewing this project through rose tinted glasses, they aren’t even hopeful of any changes being made but a large majority of them aren’t even asking for actions to be taken- they just want what they are saying to be acknowledged and simple questions they have be answered.

ILFRACOMBE COMMUNITY ENGAGEMENT EVENT

THURSDAY 13TH JULY
10AM - 4:30PM

WHAT?

Drop in to find out what is currently going on across Northern Devon to try and improve the system for those with complex needs.

This event is for you if you want to find out more, if you have questions or if you want to share your experiences and stories of working in the system or using services in Northern Devon, particularly focusing on Ilfracombe for this event.

WHERE AND WHEN?

Come along to The Lantern, High Street,
Ilfracombe EX34 9QB on:

THURSDAY 13th JULY
between 10am - 4:30pm

There will be some brief talks at the beginning of the day which will be followed by a drop in.

AGENDA FOR THE DAY

10am-11am
Short talks from:
Nikki Fuller - System Change Action Alliance (SCAA) Project Manager with Encompass

Carolyn Hurley - Core 20+ Coordinator with Encompass

Tara Rundle - Community Mental Health Development Lead with Devon Mental Health Alliance (DMHA) and Phil Harris - Recovery Practitioner for Devon Mind

Come and find out more about SCAA, Core 20+ and the DMHA

11am-4:30pm
Drop in:
Nikki, Carolyn and Tara will be around to give further information, answer any of your questions and hear from you about your experiences and what challenges and barriers you have faced.

7. CONCLUSION AND RECOMMENDATIONS

Devon Core20 + 5 Co-designed Theory of Change Objectives

Objective 1	Communities, partners, health and care providers, and decision makers have a better understanding of local needs relating to health inequalities through effective engagement, with more people having the opportunity to tell their story
Objective 2	People have a better understanding of support available, have improved confidence and motivation, and find it easier to access health and care
Objective 3	Volunteers and people with lived experiences are recognised as key contrubutors to the NHS Core 20 objectives

The co-designed Theory Of Change Framework identified 3 key impact measurement objectives at the outset of the programme. The table above applies a RAG rating to how well partners view these impact objectives were achieved during the programme delivery period.

Evidence demonstrates that impact objectives 1 and 3 above were largely achieved (RAG rating GREEN). There is less evidence to demonstrate that impact Objective 2 has been achieved at this point (RAG rating AMBER) as that relies on the 75 lived experience stories collated being analysed and responded to by One Devon NHS & partners, through a system change approach. Thinking in systems - understanding things as connected and interdependent - leads to better outcomes for all.

Recommendations & Plans and priorities for Phase 2

This report will be shared with:

- the two participating communities;
- the Population Health Management Executive Steering and Delivery Groups;
- the One Devon NHS Integrated Care System Partnership Board;
- the Devon Health & Wellbeing Board and the Torbay, Plymouth & Devon VCSE Assembly.

It is hoped that a Human Learning System approach will be applied to the 75 lived experience stories collated as part of Phase 1 of this programme, based on continuing the strengthening of local relationships and prioritising cross sectoral collaborative learning.

North Dartmoor – we will be working with the local PCN to support them with their COPD patients. The PCN will work with the connectors to support around 20/30 patients to cover key issues that affect COPD – e.g. cold homes, exercise, income etc in a very focus on the gap in service between early signs of depression and anxiety and access to support with a view to working with voluntary sector/peer support groups in the town to provide a network of services.

APPENDIX 1: EQUALITY, DIVERSITY & INCLUSION DATA PROFILE

Connector monitoring 2022-2023 Cumulative Totals		**Totals**
Please collect and collate diversity data[1] for each active connector		
Age	<18 years	0
	18-25 years	0
	26-35 years	2
	36-45 years	0
	46-55 years	1
	56-65 years	3
	>66 years	5
Ethnicity	WHITE • English/ Welsh/ Scottish/Northern Irish/ British • Irish • Gypsy or Irish Traveller • Any other White background (write in)	10
	MIXED/ MULTIPLE ETHNIC GROUPS • White and Black Caribbean • White and Black African • White and Asian • Any other Mixed/ multiple ethnic background (write in)	0
	ASIAN/ ASIAN BRITISH • Indian • Pakistani • Bangladeshi • Chinese • Any other Asian background (write in)	0
	BLACK/ AFRICAN/ CARIBBEAN/ BLACK BRITISH • African • Caribbean • Any other Black/ African/ Caribbean background (write in)	0
	OTHER ETHNIC GROUP • Arab • Any other ethnic group (write in)	0
	Prefer not to say	1
Gender	Male	5
	Female	5
	Intersex	0
	Non-binary	1
	Other gender identity (write in)	0
	Prefer not to say	0
Transgender	Yes	0
	No	4
	Prefer not to say	1
Disability	Yes	1
	No	9
	Prefer not to say	1
Sexual orientation	Asexual	0
	Bisexual	0
	Gay	0
	Heterosexual	6
	Lesbian	0
	Other	0
	Undecided	0
	Prefer not to say	5